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ABSTRACT

The research reported is an experimental study on the effects of intensified education of Swedish parents of children with amblyopia (dimness of sight without apparent organic defect) on their understanding of the nature of the disease, its origins, and treatment. Parents in the control group (n=60) were exposed to the ordinary information provided at two departments of ophthalmology, whereas parents in the experimental group (n=59), who attended the same clinics, were asked to read an informational booklet on amblyopia and amblyopia-related phenomena. Before these measures were taken, all parents were interviewed about their conceptions of amblyopia, strabismus, and the treatment. Subjects also filled out a questionnaire assessing general and specific attitudes towards disease and treatment (The Health Belief Model). After an interval of 6-8 months, these measures were repeated. Compliance with the regimen were measured after 18 months of treatment through the development of visual acuity of the children. Results reveal a superior understanding among parents in the experimental group. The experimental group also had changed attitudes toward disease and treatment in a direction that would favor compliance more than the control groups. Finally, there was a significant relationship between the parents' knowledge about amblyopia and its treatment and compliance as measured through development of visual acuity. (Author/CR)

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Vision in sight

The relationships between knowledge, health beliefs and treatment outcomes. The case of amblyopia

Anne Göransson

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Vision in sight

The relationships between knowledge, health beliefs and treatment outcomes. The case of amblyopia

Anne Göransson

Akademisk avhandling

som med vederbörligt tillstånd av filosofiska fakulteten vid Linköpings Universitet för avläggande av filosofie doktorsexamen kommer att offentligt försvaras på institutionen för pedagogik och psykologi, Eklundska salen, torsdagen den 25 november, 1999, kl. 13.00.

Abstract

The research reported is an experimental study on the effects of intensified education of parents of children with amblyopia on their understanding of the nature of the disease, its origins and treatment. Parents in the control group were exposed to the ordinary information provided at two departments of pediatric ophtalmology, whereas parents in the experimental group, attending the same clinics, were asked to read a booklet aiming at enhancing their understanding of the meaning of amblyopia and amblyopia-related phenomena.Before these measures were taken, all parents were interviewed about their conceptions of amblyopia, strabismus and the treatment. Data were generated in single subject, semi-structured, in-depth interviews which were taped and transcribed in extenso. The interviews were analysed according to the phenomenographic approach. Parallel to the interviews the subjects had also filled out a questionnaire assessing general and specific attitudes towards disease and treatment (the Health Belief Model). After an interval of 6 - 8 months, these measures with the parents were repeated. Compliance with the regimen were measured after 18 months of treatment through the development of visual acuity of the children. Visual acuity was tested by methods suitable for the age of the child. The results of the study reveal a superior understanding among parents in the experimental group. This means that they have a deeper insight into the field of amblyopia and its treatment than the control group. The experimental group had also changed attitudes towards disease and treatment in a direction that would favour compliance more than the control group. The most interesting finding in this study is the significant relationship between the parents' knowledge about amblyopia and its treatment and compliance as measured through development of visual acuity. It is also emphasised that health care personnel would profit from being aware of the nature of common misconceptions of diseases and their treatment, in the sense that they would be better prepared for entering instructional dialogues with patients or, in this case, other persons responsible for the management of prescriptions provided.

Keywords: Amblyopia; Compliance; Conceptions; Health beliefs; Phenomenographic analysis.

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Linköping, November 1999

Anne Göransson

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Chapter 1

Informing or educating patients?

An outline of the study

Patient compliance to medical treatment has become a topic of intense investigation during the last decades. Non-compliance has often been seen as deviant behaviour. A prevalent opinion has been that the patient fails to comply, because he is ignorant or forgetful (Donovan and Blake, 1992). The patient is "guilty" of noncompliance. He has been informed. The reason for this opinion is partly to be found in the view of the patient as ignorant and in need of knowledge from the medical expert. Partly, it is also to be found in the view that information is automatically expected to lead to an increase in knowledge and to a change in attitude. But above all, it is thought to lead to a behaviour in accordance with the recommendations of the medical expertise, a compliant patient. Compliance *per se* is of course not the final objective. Compliance is supposed to lead to a better state of health, if the treatment is adequate. Extensive research within the field shows, however, that the relation between knowledge, compliance and health is complex (Cameron, 1996).

Most physicians agree that knowledge about illness and treatment is of importance to compliance. On the other hand, they do not agree that these effects are only positive (e.g.Ludvigsson, 1976) or might even be negative for the patients (Williams et al, 1967). Knowledge of the illness might be strongly anxiety inducing, which can block an adequate behaviour and result in non-compliance. However, knowledge of the illness might be necessary for the patient in order to plan, carry out and control his own care in a realistic way and optimally profit from what health care offers. The feeling of security and the possibility of influencing and controlling one's life situation provided by knowledge is thought to balance the disadvantage of possibly causing anxiety. (Göransson & Riis, 1981).

Patient information is an essential part of today's health care. In the Swedish Health Law of 1982 (SFS,1982:763), it is stated that " the patient shall be informed of his state of health and about the treatments which are available"(p. 29). Fallsberg (1991) holds the view that the dominating opinion about knowledge within the health care field is superficial in nature. Knowledge is often of a denominating nature with the risk of rapid loss of knowledge and without leading to any deeper understanding. Fallsberg (ibid.) points out that knowledge of facts is necessary but not sufficient for understanding. According to Marton et al (1977) a traditional view of learning means that the individual learns facts and reproduces these facts correctly. This view can be said to be quantitative, reproducing and of an either/or nature.

One group of investigations within the compliance domain has focused on the relation between patients' knowledge and compliance. However, these studies have mostly had as their starting point a uni-dimensional view of knowledge. These studies have generally been fairly straightforward tests of factual knowledge, mostly designed as paper and pen tests including, for example, multiple - choice questions or short answer questions, that is, knowledge is only requested on a surface level. The outcome of such studies has been rather discouraging in the sense that patients seem to retain only marginal quantities of knowledge provided in the health care system (Lane & Evans, 1979; Green, 1977). Kjellgren (1998) points out, that when results from this field are interpreted, one has to observe how compliance as well as patients' knowledge have been defined and, above all, how these factors are operationalized in research.

Concurrently with the society's increasing educational level the view of the patient has changed. The knowledge gap between physicians and people in general has decreased and it has been possible for others than physicians to take part in what happens in the medical field. Even the level of demand among patients has changed and people are demanding better service from the health care sector (Svensson, 1993).

According to Dahlgren (1987, quoted in Fallsberg) learning takes place in an encounter between what is in the learner's (here, the patient's) power of imagination and what is brought about. However, it is not self-evident that the result of this meeting will be a change in the learner's opinion. For patient information to be meaningful and to contribute to the health of the patient and well-being, the health care "informants" must critically examine their view of knowledge and information to be able to develop their roles from "informants" into "communicators". One basic prerequisite of a change in communication in health care from one-way information to a dialogue, i.e. reciprocal exchange, is that the health care personnel look on the patient as a co-operation partner. Fallsberg (1991) thinks that patient information could be much better if a reciprocal understanding about what is most important in connection with a certain illness could be established. This would form a basis for presentation of facts of the disease. For instance, the conceptions of the patient which coincide with medical conceptions may be supported, while obviously wrong conceptions can be challenged and thus leave room for alternative conceptions.

With a rising interest in pedagogical activities in health care, there is room for new perspectives of learning. Hansson-Schermann (1994) describes a phenomenographic view of learning:

> The phenomenographic view of learning is that man in his relation to the world around him, in order to be able to handle it, tries to form meaning and understanding. This means that there already is a conception about what is to be learnt within the learning man. This conception is probably of another kind than the one the teacher tries to bring about. That makes the learning situation more difficult than if the learner had been empty and only needed to be refilled (p. 53) (my translation)

Learning, means that a change has taken place from one conception to another, where the latter is qualitatively different from the first (Dahlgren, 1997). From this qualitative perspective of knowledge, it becomes more interesting to study "what is learned" instead of "how much is learned".

In accordance with the view of knowledge and also learning, the view of compliance has successively changed. The more behaviouristic view early in the century, with its focus on positive and negative reinforcement has, via the focus on persuasion in the 1960s and 1970s and attitude change in the mid-1970s, shifted towards a focus on the content of individuals' ways of conceiving of phenomena as the prime factor. Now, greater emphasis is placed on the patient's role in deciding about a form of treatment. The patient should be seen as a partner who is participating in the treatment. This changed view of compliance is also reflected in the English language by the fact that "compliance" is being increasingly substituted by "adherence", which implies a more active and collaborative involvement of the patient working together with the physician in planning and implementing the treatment (Myers and Midence, 1998). The same trend can be seen in the many theories and models which have been presented to provide an understanding and explanation of the compliance phenomenon (Leventhal & Cameron, 1987).

In research where qualitative measures of patients' knowledge about disease and treatment have been used, there are indications that if the patient has understood the aims and effects of the treatment, the degree of compliance will increase (Reichard et al, 1993). Most studies trying to identify factors contributing to non-compliance, for example, with the promotion of children's health, have for the most part focused on sociodemographic characteristics of the parents and the financial and structural characteristics of the health care delivery system. There has been far less evaluation of the maternal knowledge, attitudes and beliefs that contribute to decisions to obtain preventive care (Bates et al, 1994). Most research has started from the perspective of the providers, only a few studies have so far been published in which patients' understanding of their disease and its treatment has been described.

Richt (1992) claims that good knowledge is necessary, but not sufficient for good compliance. The crucial factor is not if one has knowledge or not, but if one is motivated to use it in practice. Also important is whether a patient carries out an assessment of his/her ability to go through with the treatment and concludes that he/she is able to do so at not too much "cost".

The Health Belief Model (HBM), a theory that claims that human behaviour is the result of a process of rational thinking, was developed in the 1950s. This model provides a framework for understanding why individuals do or do not engage in different types of health-related actions. The focus of the model is on the patient and his/her relatives as decision-makers. According to Becker et al (1981) the probability of a health-related action is determined by the patient's psychological readiness to act and the experienced advantage of the treatment.

The following variables are included:

- General health motivation
- Value of reducing the threat
- Probability of reducing the threat
- Triggering impulses

As regards the meaning of these variables, Richt (1992) writes:

> (1) The experience of being biologically vulnerable to a specific illness and an assessment of the potential consequences of being hit shape, together with basic health motivation, a psychological readiness for certain actions. (2) If a high degree of readiness is given, a plan of action will be established on the basis of considerations concerning the

> efficiency and the availability of different alternatives. (3) The occurrence of impulses, which act as triggers, such as pressure from the environment and illness-related uneasiness, is of importance for the established plan to be translated into real action (Ibid p. 49, my translation)

Janz and Becker(1984) carried out a ten- year follow-up study of the Health Belief Model and found that the potentially negative aspects of a particular health action (sometimes called *perceived barriers*) were the most powerful dimension when it comes to predicting health-related behaviour. It also appeared that even if a person has feelings about the seriousness of contracting a disease or leaving it untreated (sometimes called *perceived severity*) then there is little relevance for change which contradicts an opinion sometimes expressed by health personnel, that their task is to influence the patients to make a realistic evaluation of the severity of their disease, which according to Richt (1992) means:

> Making sure that the patient really perceives his disease as serious is the same thing in practice as making sure that anxiety will serve as the basic motivation for the behaviour of the patient. (p.54. My translation)

Research has shown that if a patient understands when the effect of a treatment can be expected and what that effect could be, then compliance is supported (Wretmark, 1984). However, it is known that individuals react differently to information about how serious a disease is. Irrespective of whether the disease is described as minor or serious, the information might result in insufficient compliance. In the first case, this is perhaps due to an under-estimation of the importance of following the treatment. In the second case, due to the seriousness of the disease, the patient might feel resigned (Richt, 1992).

Hansson-Scherman (1994) used an "inside perspective" when she studied how people with asthma and allergy conceive of their disease, medicines and how to use them. Hansson-Scherman's aim was to use the knowledge obtained to improve the co-operation between the patient and the staff. She found that the behaviour of the individuals could be interpreted as a deviation from school medicine, but the overall objective was not to be compliant (to use medicine). The most important objective was to preserve one's identity as being healthy. She further found that the health of the individuals, despite deviation from school medicine, had not deteriorated. Two lessons can be learned from her study. First, in the case of patient information, one has to consider competing ways of reacting to the message in the information given. Second, the patient might contribute with knowledge that increases the understanding of the disease.

The starting-point of this study is that knowledge about and attitudes towards disease and treatment are of importance to compliance. However, compliance is difficult to measure. Many studies do not apply a stronger criterion of compliance than "coming to an agreed appointment" (see for, example, Smith et al, 1995 and Nucci et al,1992) which can hardly be seen as a satisfactory measure of compliance. It is thus important to find a field where a satisfactory measure can be found in order to study what significance knowledge and attitudes have with respect to compliance. It is also important that there is a clearly measurable connection between well-accomplished treatment and observed effect. Amblyopia in children has proved to be such a field. It could be claimed that children with amblyopia due to, for example strabismus, form an ideal group from compliance perspective since there is a well known correlation between a compliant behaviour and a positive development of visual acuity. On the other hand non-compliant behaviour will result in absence of progress - or even deterioration of visual acuity. Amblyopia implies that normal vision fails to develop because there is a difference in vision between the two eyes. Usually, it is associated with strabismus, which means a misalignment of the eyes, or anisometropia, a refractive error which is greater in one eye than the other. Amblyopia may also be a combination of both strabismus and anisometropia (Smith et al, 1995). The treatment involves patching the unaffected eye to stimulate use of the amblyopic eye and/or wearing glasses (von Noorden, 1985). Compliance is a major factor in the management of amblyopia. According to a prospective study by Lithander & Sjöstrand (1991), good compliance with any form of treatment of amblyopia was associated with a success rate of more than 95 %, regardless of age (2–7), diagnosis and severity of amblyopia. The study also showed that low compliance with any form of amblyopic treatment is the primary factor for failure in children of between 2 and 7 years of age. The measurable medical effect in this case is sharpness of vision. Absence of treatment results in an unchanged or deteriorating state of illness while well accomplished treatment results in improved sharpness of vision (visual acuity). Visual acuity in amblyopia can improve only with proper treatment.

It is known that compliance with patching treatment can be difficult. Children do not like to have their eyes occluded (Kushner, 1991). It is therefore important that the parents understand their child's disorder and the importance of the treatment. It is likely that they would be better motivated to follow prescriptions and be persistent in the treatment if they had knowledge about normal and abnormal visual development and how refractive errors and strabismus influence the visual system.

In this thesis, the results of amblyopia treatment have been compared in a study of two groups of children and their parents. The patients were quite young, which means that the parents were responsible for the contacts with the clinic as well as managing the prescribed treatment. One group of parents, the experimental group, were given information about the disease and its treatment by means of a specially designed written material (a booklet). The content of the booklet was discussed with the ophthalmologist and the orthoptist during subsequent visits, whereas the other group of parents, the control group, were instructed in the traditional way according to the normal routines at the two clinics. In both groups the information was given by the ophthalmologist and the orthoptist in charge of the treatment. The members in each group were consecutive patients at two clinics of paediatric ophthalmology, collected at different periods in time. The reason for not using a random assignment is the assumption that it would be difficult for the ophthalmologists and orthoptists after a short training course, consisting of learning and didactics, to treat the control group and the experimental group differently. Before these measures were taken, all parents were interviewed about their conceptions of amblyopia, strabismus and the treatment. They also filled out a questionnaire aiming at assessing the direction and strength of their attitudes towards their child's disease and the treatment (the Health Belief Model, HBM). After an interval of 6 - 8 months, these measures with the parents were repeated. The children were clinically examined, primarily through assessment of their visual functions at regular intervals determined by the clinic.

General purpose

The general purpose of the study reported here, is to make a systematic attempt to obtain a more comprehensive insight into the relation between how a disease and its treatment is conceived and transformed into compliance with prescriptions of treatment.

The questions examined in the study are:

- When special information about the disease (here, amblyopia) and its treatment is given, what impact will this have on the conceptions of and the attitudes towards the disease and its treatment, compared with when traditional information is given?
- Is there any relation between the conceptions of the disease and its treatment and the result of the treatment, irrespective of the way information is given?
- Is there any relation between the conceptions of the disease and its treatment and the attitudes toward the disease and its treatment?
- Is there any relation between attitudes towards the disease and its treatment and the result of the treatment, irrespective of the way information is given?

The results of the study could also have some practical application. A booklet with information about the disease and its treatment was used. The result of the use of the booklet might give cues for the future for better design of patient education about disease and treatment.

Design and data collection

The study has an experimental design with a systematic sampling procedure with a parameter of time for the sake of convenience and could be characterised as a methodological triangulation comprising both medical and instructional treatment as independent variables and compliance, measured as improvement of visual acuity, as well as conceptions of and attitudes towards the disease and its treatment as dependent variables.

The parents in the control group were exposed to the normal information provided at the two clinics of paediatric ophthalmology, whereas parents in the experimental group, attending the same clinics, were asked to read a booklet aimed at enhancing their understanding of amblyopia and amblyopia-related phenomena. The booklet was also discussed with the ophthalmologist and orthoptist at subsequent visits.

The subjects in each group were consecutively appearing children with amblyopia and their parents at the two clinics of paediatric ophthalmology, selected during different periods of time.The reason for this procedure was the opinion at the clinics that it would be too difficult for the ophthalmologists and the orthoptists to treat the experimental and the control group differently if the experimental treatment was to be given at the same time.

The collection of data on the parents' conception of amblyopia and its treatment was carried out via a semi- structured interview. The attitudes towards the disease and its treatment were measured mainly by means of an attitude scale, the Health Belief Model. There were also a number of attitude questions in the semi-structured interview. In order to establish possible changes in the parents' conceptions of and attitudes towards the disease and its treatment, these data were collected on two occasions, 6 - 8 months apart.

Ophthalmologists and orthoptists measured the visual acuity of the child using test methods suitable for the age of the child at regular intervals determined by the clinic. A final measurement of visual acuity would be made 18 months later.

Data analysis

The interviews were transcribed verbatim and analysed according to the phenomenographic approach; i.e. the outcome is a description of the various conceptions that may be discerned in the interviews. The groups were compared by combining the qualitative analysis with quantitative aspects, e.g. the distribution of subjects over categories in the pre- and post-test and in the experimental as well as the control group.

In addition to the Health Belief Model semi-structured interview questions were used to measure the motivation for treatment among the parents, i.e. their attitudes to the disease and its treatment. Beside a traditional analysis of the Health Belief Model, where mean scores were estimated for the pre- and post-tests of the experimental group and the control group, a supplementary analysis of the Health Belief Model was carried out together with the results from the interview.

Visual acuity was measured by ophthalmologists and orthoptists at the respective ophthalmological clinics, using test methods suitable for the age of the children.

Parametrical and non-parametrical tests were performed to discover whether there was any co-variance between conceptions of and attitudes towards the disease and its treatment and improvement in visual acuity.

Disposition of the thesis

In *chapter 2,* I present the field of compliance, the problems with non - compliance, problems with measurement and some models of explanations of the causes of non-compliance. *Chapter 3* describes the Health Belief Model, which was developed to explain and predict behaviour to help professionals to understand behaviour and facilitate behavioural change. The variables in the model are described and research results concerning the importance predicting compliance is presented. Finally the application of the Health Belief Model in this study is described. In *chapter 4* the anatomy of the eye is first described together with the vision of a normal eye and the development of the visual acuity in order to explain and create understanding for the following description of visual impairment. *Chapter 5* contains a description of phenomenography, the research approach that is used in this study. Design, materials and methods are presented in *chapter 6*. The results of the study are presented in chapter 7-9. *Chapter 7* presents the results of the interviews about the parents' knowledge, that is the changes in conceptions of meaning, effects and treatment of amblyopia. In *chapter 8* the results of the qualitative analysis of the health beliefs are described, where all questions appeared in the interview or in the Health Belief Model, were compiled from a number of fields which could be perceived in the whole material. In *chapter 9* the results of the measurement of visual acuity are described. This is the variable used as a measurement of compliance. In the first part of *chapter 10* a quantitative analysis of the attitude variable are presented. The second part concerns a quantitative analysis of the knowledge variable and in the third part of the chapter all relations between variables are tested. A general discussion of main result of the study and its significance and pedagogical influence on the health care is discussed in *chapter 11.*

Chapter 2

Compliance

It has long been known that many patients do not comply with treatment prescribed.

Hippocrate was aware of this when he wrote:

> Keep a watch also on the faults of the patients which often make them lie about the taking of things prescribed, for through not taking disagreeable drinks, purgative or other, they sometimes die. What they have done, never results in a confession, but the blame is thrown upon the physician (Hippocrates, On Decorum, DiMatteo, DiNicola, 1982 p. 9).

An often used definition of compliance reads as follows

> ...the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice (Haynes, 1979 p 1 -2).

Many modern investigations have also confirmed how common it is that patients do not follow prescribed treatment or apply it incorrectly, and even if there are some differences – due to the fact that therapy which includes alterations in life-style, i.e. changing of food habits, has increased the risk of non-compliance in comparison with simpler instructions like taking the medicine twice a day – the degree of non-compliance is still proportionately high.

In a review of this area, Davis (1968) found that the proportion of patients who did not carry out the treatment correctly, varied between 15 and 93 per cent. Ascbaum et al (1980) made a similar literature review and found that between 4 and 82 per cent of the patients did not behave according to the prescription. This large variation has been explained by the fact that the investigations scrutinised involved different populations, different methods for measuring compliance and a variety of diseases.

When it comes to "short-term medication regimens", Evans & Spelman (1983) found that approximately 50 per cent were non-compliant and Sackett & Snow(1979) found a level of 20 - 30 per cent non- compliance when the therapy is curative, and 30 - 40 percent when it is preventive.

When medicines are to be taken over a long period, the initial degree of compliance is about 50 per cent, but subsequently increases. This seems to apply to different types of illnesses, and in different situations (Sackett & Snow, 1979; Haynes, 1979; Norell, 1979).

In the case of "scheduled appointments", the degree of compliance, i.e. whether the patient appears at the scheduled meeting or not, the figure is about 50 per cent, if the appointments are initiated by health professionals, except when the time agreed on is for a child. If the patient himself takes the initiative to arrange a meeting, the degree of compliance is about 75 per cent. To sum up, one can usually expect that on average one third of all patients do not follow prescriptions(Stimson,1974;Blackwell,1973; Davis,1968).

Apart from the fact that these studies are not directly comparable, it is noteworthy that such a large proportion of all patients, completely or in part, abstain from following the doctor's advice or prescriptions, irrespective of whether it affects life style, career, or involves taking medicine or attending health check-ups, even though they are obviously in need of care.

The consequences of the fact that such a large proportion of all patients do not comply with prescribed treatment are not limited to the individual patients. From a socio-economic point of view, this is very costly because patients in poor health place additional strain the health care system. Bergman & Wiholm (1981) show that approximately 7-8 per cent of the patients attending a medical clinic are there because of non-compliant behaviour. Moreover, the increase in the number of days for sick leave has a negative effect on production in society.

If a medicine has minor effects, the compliance variable has little practical significance. But, if the medicine is crucial for maintaining vital physiological functions, then the medical and economical consequences of non - compliance can be considerable (Urquhart, 1996).

O'Connell and Bristow (1994) have, for example, shown that the average cost of each hospitalisation for complications of congestive heart failure is US D 10.400.

Furthermore, there is an obvious risk of a doctor interpreting a negative result of the treatment as signifying that the medicine had not had the expected therapeutic effect, which might lead to repeated examinations and/or new medicines. Besides, it might influence the clinical evaluation of the medicine concerned. (Urquhart, 1996; DiMatteo & DiNicola, 1982).

It is thus more economical to try to reduce the effects of different courses of a disease through medical treatment, and by means of measures which make the patient follow the prescription given than to assign more care resources than warranted by the illness to the patient. This also applies in cases where it may not be possible to entirely cure the illness, but where compliance with the prescriptions would have reduced the symptoms of the disease.

The compliance concept

In the medical and pharmaceutical field, the concept of *compliance* is used as a uniform concept to indicate that the patient adheres to the therapeutic prescription. Other terms used to describe the same phenomenon are *adherence*, *obedience* and *co-operation*. Some researchers have maintained that these expressions are interchangeable (Sackett & Haynes, 1976), while others think that compliance means almost implicit obedience by the patient (Myers & Midence, 1998) Compliance, however, is the term most frequently used in the literature and will therefore be used in this study.

In the behavioural sciences (e.g. Kelman, 1961) compliance is defined as the lowest level in a hierarchy of concepts consisting of three levels which describe the degree of personal involvement in a behaviour. The intermediate level is the concept of "identification" and the highest is "internalisation".

In Kelman's view, the degree of intensity and resistance of the behaviour of an individual depends at which level attitudes towards the behaviour are. An individual at the *compliance* level changes his behaviour to attain a positive reaction from this surroundings. This does not mean that the individual has changed his attitude or is convinced that what he does is correct. His behaviour often only becomes visible in public situations.

For an individual who reaches the *identification* level, what is most important is the attainment of a desirable relation with the part who exercises influence, which is a matter of importance for his self-estimation. Here, the behaviour is expected to be expressed as long as the individual's relation with the person, whose influence is desirable, lasts.

The highest level in the hierarchy, *internalisation*, means that the individual changes his behaviour because the "message" fits into an existing value system. Here, it is the content, the message, instead of the intermediary of the message, as in the case of compliance and identification, that is relevant. This results in a behaviour more resistant to influence.

Of course, it is preferable that the patient internalises a way of carrying out the treatment of his illness, where doctors, nursing staff and pharmacists are seen as partners in the treatment work, rather than superiors who control him (DiMatteo & DiNicola, 1982).

Henceforth, the compliance concept will be used, if not stated otherwise, in accordance with common use i.e. as an integrated concept without any distinction of level. Compliance means that the patient carries out the treatment prescribed.

Non-compliance

If compliance is defined as adhering to the prescriptions provided, it would be easiest to define non-compliance as a situation where the patient does not adhere to the prescriptions. It may take the form of a delay in seeking care, not applying preventive measures, not coming to agreed appointments or not following treatment prescriptions (Gordis, 1979).

The last-mentioned aspect may appear in several ways,(Kass & Becker, 1976; Boyd et al, 1974; Schwarz et al, 1962).e.g.:

1. Neglecting to take medicine. This includes forgetting doses and early interruption of the therapy.
2. Excessive medicine intake: The patient increases the dose, perhaps with the hope of increasing the beneficial effects of the medicine.
3. Wrong interval when taking medicine: The medicine is not taken at the specified times during the day and at night.
4. Taking medicine for the wrong reasons: A patient who is given several different medicines might confuse the reasons for taking them, e.g. taking antibiotics to cure a headache.

Naturally, the above do not only apply to taking medicine but also to all kinds of therapy.

Some researchers (i.e. Gordis, 1979) emphasise the importance of differentiating between non-compliance and plain errors in medicine taking, where the patient, despite his intention to follow the prescription has not managed to do so. This might depend on the prescriptions being too complex or other elements having confused the patient.

The result, that the treatment is not followed, is the same irrespective of the patients' intentions.

Bigger (1976) writes:

> Unless we are aware of and able to manage noncompliant patients, our ability to alter disease outcome will be limited (p. 280).

Problems in measuring compliance

In research on compliance, two of the problems encountered are:

- How to define compliance in the case of the specific disease?
- How to identify patients as "compliers" and "non-compliers", respectively?

It is hard to establish adequate criteria for measuring compliance. Whether using direct or indirect methods, it has been hard to find methods which produce a reliable result.

Gordis (1979) holds that direct methods for measuring compliance e.g. blood levels and urinary excretion of medication, metabolites and markers are often not enough. One reason is that there is seldom any linear connection between application of treatment and unambiguous, measurable medical results. Pharmacokinetical variations, that is, individual differences in absorption, distribution, metabolism and separation of medicines mean that tests of patients, even if they have the same disease, are not automatically comparable.

Among the indirect methods are therapeutic or preventive outcome, the impression the physician gets (predictability), interview with the patient, and pill count. A fairly recent method, which makes it possible to measure compliance over time, is a pill box with an electronic device in the lid. (Stephenson et al, 1993).This box automatically counts the pills when they are taken, although there is no way of knowing whether it is the patient or somebody else who has taken the medicine. There are no indirect measures of compliance that are considered to be reliable. In the case of most diseases/injuries, it is not enough to only study the result of the treatment since it is not possible to determine what treatment factors are the result of compliance or socio-economical and cultural factors. In cases where there is direct connection between compliance and result, this relation ought to be made clear.

It should be realised that the effect of non-compliance also depends on how close the quantity of e.g. medicine is to the minimum needed to achieve the optimum therapeutic effect. If the quantity prescribed is less than this minimum, a low degree of compliance will not reduce the effect of the therapy.

Proceeding only from interviews with patients in order to discover whether the treatment has been applied or not is not a satisfactory method due to a too large subjective element since there is a risk of patients remembering incorrectly, give socially acceptable answers, etc.

The inability of physicians to identify which patients apply the treatment and which patients do not has been shown in many studies (i.a. Mushlin & Appel, 1977; Caron & Roth, 1968) . This means that even this indirect method has very limited value.

Nor has comparing the amount of medicine left in the package with the amount which ought to remain if the patient has applied the treatment correctly proved to be a useful method for measuring compliance. There are, for example, occasions when people other than the patient use sleeping medicine and antibiotics. Moreover, it is not possible with this method to confirm whether the patient has taken the medicine at proper intervals.

Determining which patients should be regarded as having applied the treatment and which have not can also be difficult. Gordis (1979) describes three methods which have been used.

1. Series of tests are made on the patients and the proportion of positive tests is fixed. The population can then be dichotomised on the basis of the level of compliance needed to achieve a therapeutic effect. This type of data is, however, often hard to obtain.

2. Dichotomisation can be made on a statistical basis, through fixing the mean level of compliance in a group of patients as the cut-off between compliant and non-compliant patients.

3. An arbitrary level is chosen so that a certain percentage of positive tests for a patient is defined as evidence of compliance. This is a method often used.

The causes of non-compliance

Studies of what factors might have a connection with compliance and non-compliance, respectively, shows that it is not possible, on the basis of characteristics such as age, sex, marital status, education and profession, socio-economic level, religion or race, to predict which patient will or will not apply the treatment (Hulka et al, 1976; Marston, 1970), although there are some studies showing that non-compliers have typical demographic features (Cramer, 1991; Lüsher and Vetter, 1990. However, it seems that psychological and emotional factors play a larger role for compliant behaviour than demographic features (Evans and Spelman ,1983).

DiMatteo & DiNiccola (1982) hold the view that the research results in this field can be combined into three models for explanation. One model seeks an explanation of non-compliance in *intrapsychic factors* such as thoughts, feelings and attitudes. Becker (1974) holds the opinion that the individual's attitudes and beliefs about the susceptibility and severity of a disease and the costs and benefits of the treatment determines how the individual will act. Stone (1979), feels that another source of non-compliance is misinformation and incorrect beliefs. Another explanation in this category is that the resistance of the patient could be explained in terms of a desire to take control of a situation of which he thinks he has lost control.

A second model of explanation assumes that the reason for non-compliance can above all be sought among *environmental factors*. For instance there might be other demands on the patient's time, interest, money, etc. Socio-cultural explanations can also be added, i.e. those that emphasise the significance of cultural and social support of compliant behaviour (Stone, 1979).

A third model is based on the *practitioner-patient relation* as regards causes of non-compliance. Svarstad(1976) for example, emphasises the physician's difficulties in giving information to the patient.

Lane (1982) found that physicians try a variety of strategies to gain compliance from patients: a) Give the patient a thorough explanation b) inform the patient of the benefits of the advice c) get tough and d) withdraw.

If the patient is still non-compliant, the physician usually a) overwhelms the patient with knowledge b) tells the patient about the dangerous effects if the patient does not comply, c) tells the patient that he is aware of the non - compliance or d) uses personal persuasion tactics.

Roter (1989) has carried out a meta-analysis of a large number of physician-patient studies which indicates that compliance was positively associated with information giving and positive talk and negatively associated with question asking and negative talk.

It is not unusual for people to utilise any form of cognitive defence against adhering to treatment, treatment which is perhaps regarded as being difficult to follow such as a change of life-style. Dahlgren(1990) discusses three such mechanisms, *Episodic evidence* which means that a single occasion or case might be more credible evidence than the results of all research. An example of this is when an aged relative, who smoked all his life, and is still healthy, is used as proof that all scientific research stating that there is a connection between smoking and unhealthy is wrong.

A smoker who defends his tobacco consumption by " if I do not smoke more than five cigarettes a day, it is not harmful to my health!" is an example of the second mechanism, *differentiating*. The third mechanism is *relativity of knowledge*. An individual who thinks contradicting research results in the same field proves that you cannot trust anything, so why not go on living in the same way, is referring to this mechanism.

Information in the health care sector is given to guide and influence the patient in a certain direction, but research on compliance shows that the relation between knowledge, compliance and health is a complex phenomenon (Cameron, 1996).

It is known that knowledge may influence health status. There are, however different opinions as to whether this effect is only positive or whether it may also be negative. Some studies on diabetics' knowledge of their disease show that knowledge might have a negative effect (Williams et al, 1967). Other investigations support the opposite point of view, that an increase in knowledge has a positive influence on the patients' acceptance of their disease and of the course of the development of the disease (Ludvigsson, 1976).

Many studies, however, show that a patient's understanding of his own treatment is often inadequate, with misconceptions and misinterpretations being the rule rather than the exception. Wretmark (1984), for example, found that the patients soon after a visit to the physician had forgotten almost half the information or had never understood it. Likewise Svarstad(1976) found in interviews with patients a few days after they had received information from a physician that 50 per cent did not know how long they were to take the medicine, 26 per cent did not know the right dose, 17 per cent did not know when to take medicine and 25 per cent did not know which of the medicines they had been given had an effect on which disease. Leid (1986), found that 1/3 of the patients in her research group who used diuretics did not know that this preparation increased the production of urine. Potassium is often confused with calcium so patients believed that potassium preparations were good for the bones and therefore often continued to take this tablet even after the treatment with diuretics should have ceased. (In Swedish the words are similar: kalium and kalcium).

Eustis and Smith (1987) studied how much parents understood about strabismus and found, among other things, that most parents could identify impaired depth perception as the most significant problem caused by strabismus, and, as the authors say, this is the most important reason for having surgery but many misunderstandings were also found, for instance, 16 per cent of the parents did not know whether the eye was removed from the head during strabimus surgery. The authors thinks that it is not realistic to believe that all relevant information could be understood by all parents.

A view like this might give as result that patient education will be more focused on behaviour than on knowledge. This view is also more in correspondence with the behaviourist theory, where the human being is conceived of as passive, non-reflective and without ability to judge the incoming information.

Chapter 3

The Health Belief Model

A description of the model

Within the social and behavioural sciences, several models and theories have been developed to explain and predict the behaviour of individuals. The goal of these models is to help professionals to understand behaviour and facilitate behavioural change. One of the most frequently used models of health behaviour is the Health Belief model. The model was developed to explain health-related behaviour at the level of individual decision making. The model was originally developed in the early 1950s by a group of researchers to explain the low levels of participation in preventive health services such as screening tests and immunisation offered by U.S. Public Health Service (Rosenstock,1990,1974). The aim was to explain preventive health behaviour of individuals who at the time were not suffering from a disabling disease. This model belongs to the rationale belief models (Leventhal, 1987) because it is based on the idea that human behaviour is determined by a logical, objective thought process. The model was strongly influenced by the theories of Kurt Lewin. It has a phenomenological orientation, so that it is the subjective world, the world as perceived and not the objective world, that determine behaviour (Rosenstock, 1974). In the social psychology theory of Lewin, the individual is thought to exist in a life space composed of regions, some positively and some negatively valued and others with a neutral value. Depending on their value, these regions will affect a person's behaviour. Diseases were regarded as regions of negative value while an action to avoid a disease would create a positive region. (Maiman & Becker, 1974).

The variables in the Health Belief Model are based on a special case of Lewin's theory of goal setting in the level-of-aspiration situation(Rosenstock, 1966). Level-of-aspiration is defined by Deutsch (1968) as a familiar task's level of future performance that an individual explicitly tries to reach.

In the level-of-aspiration situation, a person decides which levels of difficulty are appropriate on the basis of the relative valence, i.e. the subjectively assessed desirability of these levels and the subjective probability of success or failure at each level. Usually, people tend to aspire to levels close to slightly higher than their earlier performance level.

According to Rosenstock (1960), Lewin assumed that two major variables influence behaviour,1. The value of the outcome to a person. 2. The person's estimation of the probability that an action will result in that outcome.

Rosenstock (1975) assumes that the probability that an individual will take action towards achieving a goal is determined both by the person's psychological state of readiness to take action, and by the perceived benefit weighed against the perceived costs of action.

In the case of health behaviour, the psychological state of readiness to take action is influenced both by perceived susceptibility to the specific health condition and the perceived severity of the consequences of contracting the condition.

If the individual does not believe in personal susceptibility and serious repercussion of illness, the action will not occur. A benefit for a person might be, if he takes action, his evaluation of the recommended action in terms of its feasibility and its power to reduce the threat. The perceived benefit is weighed against the perceived physical, psychological, economic and other costs and barriers against taking action.

It is also proposed (Mikhail, 1981) that there must be some kind of stimulus for the behaviour to occur. These stimuli can be internal or external. Internal stimuli can be an individual's perception of the physical state. External stimuli can, for example, be interpersonal interactions. If a person has a high psychological readiness to act towards achieving a goal, he will require only a slight stimulus.

There is a group of factors that will influence the individual's perception of susceptibility, severity and benefits of taking action (Becker et al, 1977,b; Becker and Maiman, 1975; Becker, 1974). These modifying factors are, according to Mikhail (1981):

> 1. demographic variables
> 2. structural variables, such as complexity and side effects of the regimen
> 3. attitudinal variables, such as satisfaction with clinic staff and procedures
> 4. interaction variables, such as quality and type of patient-provider relationships
> 5. enabling variables, such as source of advise and social pressure. (p. 68)

Health motivation was introduced into the model by Becker et al (1974). The idea was that motives determined an individual's degree of interest in health behaviour because of his perception of his health. Attaining (or maintaining) good health and avoiding illness is a dimension of health motivation.

The most important dimensions of the model that have been developed to explain health motivation are:

1. The extent to which an individual believes he is susceptible to a disease.
2. How serious an individual believes that a disease would be.
3. How beneficial an individual thinks certain actions would be in reducing the susceptibility to or the severity of the disease.
4. Perceived barriers or costs.
5. Cues or stimuli to action.

Perceived susceptibility : Individuals' perception of susceptibility to a disease has been found to be positively correlated with compliance with a variety of recommendations such as taking part in screening for cancer (Fink et al, 1972; Flach, 1960), tuberculosis (Haefner and Kirscht, 1970), heart disease (Haefner and Kirscht, 1970) and participation in preventive health care actions such as obtaining immunisation (Cummings et al, 1979; Larsson et al, 1979; Rundall, 1979; Rosenstock et al, 1959 among others).

When the diagnosis of illness has already been made, new dimensions of personal vulnerability must, according to Becker and Maiman (1975), be added:

1. Examining the individual's belief in the diagnosis (perhaps the patient does not trust the diagnosis and/or has no confidence in the physician).
2. The individual's belief in the probability of a recurrence of the disease if he has had it before.
3. Examining the individual's vulnerability to other diseases or to illness in general.

Perception of susceptibility or resusceptibility to a disease has been found to be positively related to compliance with the therapeutic recommendations. From a number of studies, it is obvious that parents who have a rather high perception of their children's' susceptibility or resusceptibility to a disease are more likely to be compliant with the medical regimen.

Studies that support this statement are, for instance, Becker et al (1974) in a study of children with otitis media, by Elling (1960) in an asthma study, and by Becker et al (1977,a) in a study of obese children.

This variable, perceived susceptibility, has both an explanatory and a predictive value, as it is based on a number of empirical studies, and it is important as a measure in a psycho-social compliance model (Becker and Maiman, 1975).

Perceived severity : This variable refers to an individual's personal perception rather than to any 'objective' estimation of the seriousness of the disease. It is obvious that compliance will not occur unless the person believes that becoming ill would bring serious medical and/or social consequences.

Many investigations have focused on the relation between perceived severity and compliance, and relate to compliance with both health recommendations and prescribed medical therapies. The results are not consistent. The findings relating to perceived severity and compliance with preventive health recommendations are mixed. Significant correlations have been found, for example, in studies involving health recommendations with dental care (Becker, 1974; Tash et al, 1969; Kegeles, 1963) but not in different types of screening programs (Kabach et al, 1974; Haefner and Kirscht,1970; Hochbaum,1958).

Other studies have shown that an individual's estimation of his present disease can be used as a predictor of compliance with a prescribed medical regimen. Becker et al (1974, 1972 a, 1972 b), Francis et al (1969), Gordis et al (1969) and many others have also shown that parents' perception of the severity of their child's illness is positively related to the parents' compliance.

An explanation of these results could be that somatic symptoms bring a more realistic component to perceived severity. It is also known that many patients, after a while, when they feel better, act non-compliantly; the estimation of the seriousness of the illness has changed.

Another finding is that extremely high and low levels of anxiety do not bring about a compliant behaviour (Ley and Spelman, 1965). The results as regards preventive health behaviour and sick role are similar. The explanation might be that individuals use different defence mechanisms such as denial and repression of the physician's prescription.

In summary, the variable perceived severity, used as a predictor of compliance, appears to be useful in some preventive investigations and in an overwhelming majority of investigations into disease conditions. Perceived severity should thus be part of a model of compliance.

Perceived benefits and barriers : The beliefs about the efficiency of the therapy and the beliefs about the difficulties in carrying out the therapy have an influence on compliance (Becker and Maiman, 1975). Kegeles (1969) found a positive correlation between women's beliefs in early detection of cervical cancer for a better prognosis and a trust that a test could detect the disease, and participation in a cervical cancer screening program.

In a number of studies, the perception of benefits was also shown to be associated with compliance with therapy. Two investigations reported positive correlations between belief in the ability of penicillin to prevent recurrence of rheumatic fever and compliance with therapy (Heinzelman,1962; Elling et al,1960). Another study by Becker et al (1974) showed that "belief in efficiency of the medications" was positively associated with compliant behaviour. In summary, the beliefs about the perceived benefit of an action have an influence on people's willingness to be compliant with actions to prevent, detect or treat a disease (Mikhail, 1981).

Barriers are factors that give rise to a negative feeling towards an action. An action may be seen as a tool to reduce the threat of a disease, but it could be inconvenient, painful, expensive and upsetting. These barriers could give rise to conflict-avoidance motives (Rosenstock, 1974). Non-compliance is not uncommon among individuals who believe that a medicine or another kind of regimen is not safe or has some side effects (Rundall, 1979; Taylor, 1979; Becker et al, 1977,a; Kirscht & Rosenstock, 1977).

Health motivation: Concern about health in general, has been found to have a positive correlation with preventive health behaviour(Harris&Guten,1979; Ogionwo,1973) and with compliance to medical regimens (Becker et al,1978; Becker et al, 1977,b ; Becker et al,1972, b). Belief in personal control over health matters has also been found to be positively correlated with compliance (Becker et al,1975). Some other investigations have nevertheless showed that there is no relation between concern with health and compliance (Rundall & Wheeler,1979) or belief in a personal control over health matters and compliant behaviour (Becker et al, 1974). These inconsistent findings may be due to the fact that the concept "health motivation" is hard to operationalise.

Cues to action: It has been found that even if the levels of susceptibility and severity are high and the benefits are experienced as greater than the barriers, some sort of cue appears to be necessary to start an action. These cues might be internal, for instance, that you feel some somatic symptoms, or external, such as health campaigns in mass media or a reminder from dentist. How strong a cue is needed is often related to perceived susceptibility or seriousness of a disease. If you consider yourself to be in the danger zone of a disease, and believe that it might be serious, the cue does not need to be particularly strong, whereas the opposite is the case when one does not regard an illness as dangerous and does not believe that one will be affected by it (Salazar, 1991; Becker, 1974).

Modifying factors : Many additional variables have been tested but according to Becker (1974), only demographic, structural, attitudinal interaction and what he calls enabling factors (variables which either affect sociobehavioural dimensions or in themselves are sociobehavioural variables) have proved to be useful. An example is *the relationship between doctor and patient;* if the doctor is felt to be negative or formal, it might have negative influence on compliance (Davis, 1968). For mothers carrying out the therapy prescribed for their children, it was also important that the doctor showed empathy (Frances et al, 1969). Also the *continuity of physician,* which means that the patient meets the same doctor when re-visiting the clinic, is of importance to compliance (Becker et al, 1972,b ; Charney et al, 1967). *Social influence* ,family members or friends supporting the patient in following prescriptions also have a positive effect. Even group pressure at preventive health examinations, e.g. mammography (Bond,1965), has proved to have positive effects on compliance. *Demographic variables* such as sex, civil status, education, profession, socio-economical level, religion or race, have mostly not turned out to be useful in predicting compliance (Marston, 1970). In the case of age, only extremes of ages, such as very old and very young patients, have shown any correlation with non-compliance (Blackwell, 1973).

Usefulness of the Health Belief Model

Janz and Becker (1984) made a survey of 46 Health Belief Model-related investigations. One limitation, however, was that they only studied the relations between the four basic HBM structures: perceived susceptibility, perceived severity, perceived benefits and perceived costs or barriers. Janz and Becker(ibid) have calculated a "significant ratio": "wherein the number of positive and statistically significant findings for an HBM dimension are divided by the total number of studies which reported significance levels for that dimension"(p.36).

As regard to sick-role behaviour, it was found that perceived barriers had the greatest importance (91 per cent), perceived severity followed next (85 per cent), perceived benefits and perceived susceptibility were rated almost alike 75 and 73 per cent, respectively.

The fact that perceived susceptibility was rated so low has been explained by difficulties in operationalising the concept of vulnerability when the diagnosis is made. Circumstances are quite different when it comes to preventive health care where the significance ratio of susceptibility was 100 per cent.
Janz and Becker(1984) summarise their discussion thus:

> Overall, these investigations provide very substantial empirical evidence supporting HBM dimensions, as important contributors to the explanation and prediction of individuals' health-related behaviours (p. 41).

Some criticism has been levelled at the Health Belief Model, for example, that it is based on the assumption, that health is always positively valued and diseases negatively valued. That might not always be the case. Mechanic (1968) shows that diseases in certain cases provide the patient with secondary gains such as sympathy and attention. This does not need to be a conscious process carried on by the patient. There are also many other factors that can influence health behaviour, for example, individuals may choose to diet, not for their health but because they will look better if they lose weight. A further criticism of the model is that it defines motivation as a combination of likelihood and severity of beliefs.

Another limitation of the model is that it does not address the issue of coping skills – it focuses on rational, intentional behaviour and does not take into account the spontaneous activity that can occur among people (Salazar, 1991).

Recently another variable has been added to the Health Belief Model. This variable is the concept of *self-efficacy* (Rosenstock, 1990). This concept has been described by Bandura (1982). Bandura argued that people's expectations of mastery and achievement, their convictions about their own effectiveness, influence the ability to perform a behaviour. A strong sense of self-efficacy allows an individual, according to Bandura, to feel free to select, influence and construct the circumstances of their lives (ibid). Janz and Becker(1984) are of the opinion that self-efficacy can be looked upon as a an aspect of "perceived barriers".

Above, only the effects of the different components in the Health Belief Model have been described, but it has also been found that combinations of "beliefs" in many cases increase the predictive power. So Heizelman (1962) describes how the patients view of " resusceptibility" to rheumatic fever and the seriousness of the illness had a clear connection with taking penicillin with the aim of prevention.

The Health Belief Model can be used in the medical care to try to identify patients who might be non-compliers. The next step will be to influence the patient's perceived susceptibility to and his perceived severity of the disease by providing him with adequate knowledge about the disease and its treatment. This might result in a decrease of the perceived threat. Similarly, one can try to imagine what barriers the patient might feel exist, and for instance by a dialogue get the patient understand what effect these barriers might have for the treatment of the disease.

The application of the Health Belief Model in this study

The Health Belief Model was originally designed to study how patients tried to avoid a specific disease. It has been modified by Becker et al, (1972, a, b), by introducing the concept of *General Health Motivation, Value of Reducing the Threat* and *Probability of Reducing the Threat.* Becker et al (ibid) used this revised model in a study of mothers with children who took penicillin for otitis (inflammation of the ear). The compliant behaviour of the mother is expressed as dependent variables. This is described as the probability of the mother supplying prescribed medicine and continuing to keep appointments. Independent variables are the mother's motivations which are assumed to influence compliant behaviour. These motivations are divided into the following categories:

General Health-Related Motivation, which means that different degrees of readiness to undertake a health action are brought about by health cues. The sub-headings of General Health Motivation are: Physical threat (experience the feeling of), Control over state of health (have the feeling of having), Medical motivation (have), Anxiety about general state of health (anxiety concerning the child).

The Value of Reducing the Threat, which comes from the idea that if the mother experiences the child's disease as threatening, it should be an incentive to reduce the threat.Value of Reducing the Threat has the sub-headings: The child's vulnerability, The degree of physical injury in the case of the child, Interference in the social roles (as regards the mother).

The Probability of Reducing the Threat, was the mother's perception of the probability of reducing the threat through compliant behaviour. Probability of Reducing the Threat has the sub-headings: Confidence in the diagnosis, Experience of the effect of the prescribed medicine/treatment, Belief in modern medical science.

The revised Health Belief Model also includes *health motivations* which include concern about health matters and the individual's interest in seeking medical care, *modifying and enabling factors*, which include demographic variables and the patients' attitudes towards the care provided. The structure of care is also considered.

The idea was that this revised model would be of use in accounting for and predicting compliance in paediatric care, both on a general level and in the case of specific diseases.

Therefore the same variables are used in this study of amblyopic children and their parents.

The following variables of the Health Belief Model are used: Motivational factors, threat level factors and factors affecting threat reduction The general modifying factors are presented in the summary of the thesis.

The Health Belief Model, which is used in the present study, is presented in figure 1.

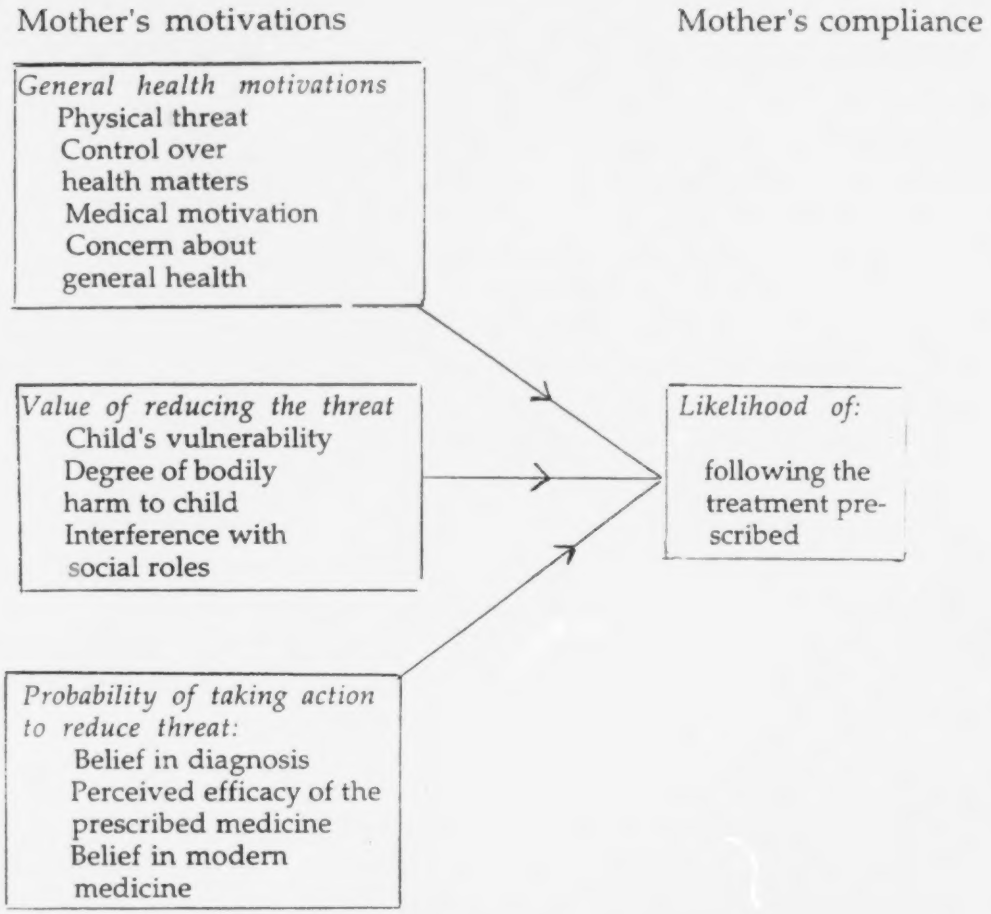

Mother's motivations
Mother's compliance
General health motivations
Physical threat
Control over health matters
Medical motivation
Concern about general health
Value of reducing the threat
Child's vulnerability
Degree of bodily harm to child
Interference with social roles
Probability of taking action to reduce threat:
Belief in diagnosis
Perceived efficacy of the prescribed medicine
Belief in modern medicine
Likelihood of:
following the treatment prescribed

Figure 1. Health Belief Model reformulated to predict compliance of mothers of pediatric patients (Becker et al, 1972). (The Likelihood of following the treatment prescribed, has been summarized by the author)

The Health Belief Model has been revised by many authors. Often, the change consisted of adding new variables, not always logically related to the original model.

The need for these additional variables indicates that beliefs and subjective perceptions are not sufficient to predict compliant behaviours. The purpose of adding these new factors is to increase the validity of the method.

According to DiMatteo & DiNicola,(1982),the factor health motivation, has received strong empirical support while some of the variables added in revised models are considered as"..... poorly conceptualised variables, unclear in their theoretical formulation and weak in their empirical measurement." (p. 134).

Horne and Weinman (1998), claims that the cognitive variables in the Health Belief Model may be prerequisites of compliance in some situations. One limitation is that the Health Belief Model simplifies health-related cognitions into "benefits" and "barriers" while other cognitions also are likely to be salient.

Chapter 4

The visual disability

At least 2 - 5 per cent of all pre-school children are estimated to have reduced vision in one eye as a consequence of amblyopia (in Greek the noun amblyos means blurred and the verb ops means see). Amblyopia means that visual acuity as well as depth of vision are negatively affected (Thomson et al, 1991; von Noorden, 1985).

Poor vision limits choices in many areas. It limits the choice of profession – some professions such as that of pilot, engine-driver and radar operator require that the individual have perfect vision in both eyes. The same applies in some sports, above all ball games such as tennis, table tennis, football and basketball where good vision is needed. There are also negative consequences from a psychological point of view, e.g. it often causes anxiety about possible injury to the good eye.

The child's visual capacity could influence its school situation as well as choice of profession and hobbies. It is thus just as important to treat amblyopia as it is to treat an eye injury. To be effective such treatment must take place before the age of seven to eight years.

To understand amblyopia and its treatment a description of the function and anatomy of the eye, the development of visual acuity and the most common reasons for impaired vision is here presented. This presentation follows the content of the information booklet which was the product of the co-operation between the author of this thesis and three ophtalmologists.

The anatomy of the eye

The visual organ is composed of the eyeball and the optic nerve. To make the visual organ function, a number of so-called accessory organs have developed, which directly or indirectly are important to vision. These organs are the muscles of the eye which control the movement of the eye, the eyelids and the tear gland.

The light refractive parts of the eye are
- the tear fluid
- the surfaces of the lens
- the substance of the lens
- humor (corpus vitreum)

The cornea can be described as a firm lens, and accounts for more than 2/3 of the eye's visual acuity where the lens in the eye (lens crystallina) which can change its thickness, has just under half the refraction capacity of the cornea (Karpe,1972). The lens, however, plays a very important role in the acuity *changes* of the eye.

When you want to see clearly close up, the shape of the lens changes and becomes thicker; when you look at an object at a distance, it gets thinner - the lens accommodates. In the case of short-sightedness, the eyes are also turned inwards towards the root of the nose - they converge - when observing something close. Accommodation and convergence are therefore connected.

The amount of light reaching the retina is regulated by the pupil-the opening of the iris. The brain regulates the dimension of the pupil by means of signals from the retina about the intensity of light. Strong light makes the pupil smaller when you look at an object close up, which increases the depth of acuity.

The retina is placed on the back wall of the eyeball. It contains cells, rods, sensitive to light which are primarily used in darkness, and cones which are most important for colour and detail vision The cones are most concentrated in the centre of the retina, the so-called *macula lutea.* In the middle of this is *foveacentralis,* where visual acuity is at it's sharpest.

The mobility of the eye

The eyeball is moved by six muscles, four run straight, and two obliquely through the socket. Normally, the muscles cooperate so that the eyes follow each other during movement.

The eyes, therefore, cannot move independently of each other - the mobility of the eyes is always co-ordinated (conjugated). The co-ordination of the muscles, which directs the eyes to a precise position, enables the eyes to converge, that is, the ability of the brain to merge two pictures from each eye into one picture.

In new-born children, the position of the eye is not stabilised, the eyes can be in a strabismic position, i.e. both visual axes are not directed towards the object. The reason for this is probably that the retina has not yet developed and that binocular vision is poor during the child's first month. At about 3-6 months of age the eyes are usually co-ordinated.

The vision of a normal eye.

Light is one of the conditions for seeing. Normally, a distinction is made between direct light, when the light enters the eye directly from a source of light, and reflected light, where the light first strikes an object and is then reflected. Most of the visual information about the surrounding world comes via reflected light.

Visual sensations are the result of a process in several steps. The ray of light passes through the cornea and the pupilage and strikes the lens. The lens has, as mentioned above, the ability to change its form, to become thinner or thicker. In this way the refraction can be varied so that a sharp image strikes the retina.

When the light strikes the retina it causes chemical signals, which pass through the optic nerve to the visual centre in the occipital lobe. There they become conscious sense impressions, which are perceived as turned right.

The development of the visual acuity

When the child is born, visual acuity is low because the retina and the visual centre in the cerebral cortex are not fully developed. The development of eyesight proceeds slowly. The visual acuity in newborn babies is 0.1 and at two years about 0.3 and does not reach about 1.0 until four years of age. The reason for this is that the macula is not quite differentiated at birth, but is like the rest of the retina where visual acuity is much less sharp. The development in the macula area means that the cell layers which are located innermost are pushed aside and the central group (fovea centralis) is created. However, the macula is not wholly developed before the age of five.

The visual path and the visual cortex develop at the same time as the retina develops. From the cells of the visual cortex, dendrites, other cells sprout. If this coupling between the cells is used for transmission of information, the contacts are made permanent. If the contact areas are not used, they develop badly because there is a too small quantity of the substances needed for transmission of information. So normal neuronal function is needed for the anatomical structure to develop. (Hyvärinen, 1983).

For this development to take place, the following conditions must be satisfied: a sharp image must strike the middle of the retina (the fovea). It is only there that reproduction can have maximum detail resolution.

The images that strike the retina are two-dimensional, i.e. they have both width and height. However, you do not see the same image with each eye - the images are slightly dislocated in relation to each other. This is easily seen if you alternatively shut the right and the left eye.

The images, which are not exactly alike - are transmitted by nerve impulses to the visual centre of the visual cortex. Nerve impulses from the right part of both retinas are transmitted to the right half of the brain, and nerve impulses from the both left retinas are transmitted to the left half of the brain. In this way, the information from both eyes merges and the images from the two eyes are combined to form one image in the brain.

This image has breadth, height and width - which means that depth of vision or stereo vision has been created. The neurological basis of the co-ordination of the two eyes is already developed in a new-born child, but it has been found that the child does not have stereoscopic vision until the age of a couple of months. The ability of binocular vision is developed if both eyes are used to the same extent and the images are fused into one picture.

During the first year, the movement of the eyes is also developed. The fixation reflexes, which are fundamental to normal development of vision, exist already at birth. Most new-born children fix their eyes on an object and are capable of following it when it is moved horizontally before their eyes. A few new-born children can follow an object which moves vertically, but it often takes 4-8 weeks before this ability is developed. Up to one year of age, it is hard for a child to keep its eyes fixed on a moving object, and it follows the movement more slowly than do adults.

Much of the development of vision takes place during the child's first year, but further development and fine adjustments are estimated to occur up to the age of seven. Thereafter, it is no longer possible to influence the development of the visual cells in the visual cortex. This means that the vision of a child, impaired by a visual defect, cannot be improved by treatment after this age. In other words, the visual impairment is permanent.

The causes of visual defects

There are three causes of visual defects: refractive error, amblyopia and illness or injury. Here, only refractive error and strabismus will be described.

Refractive errors:
In an eye with normal vision (emmetropia), the optic parts (cornea and lens) and the length of the eyeball are well-adapted to each other. The rays of light refract in a way that gives good visual acuity both close up and far away. With refractive error, the image is not focused on the retina, but in front or beyond it. The image which then strikes the retina is blurred. As a result, the visual system does not develop normally.

Nearsightedness (myopia) is often caused by the eyeball being too long in relation to the refractive power in the cornea and the lens. The rays from an object are refracted so that the sharp image lies in front of the retina, and the image that strikes the retina is blurred because the rays are spread again. The treatment for nearsightedness is spectacles with spreading (diffusing) lenses (-glasses) which correct the rays so that a sharp image appears on the retina.

Farsightedness (hypermetropia) is often caused by the eyeball being too short in relation to refractive power in the cornea and the lens. The rays from an object are then refracted so that the sharp image lies behind the retina, so the retina becomes blurred.

If farsightedness is not severe, the eye can gather the parallel rays, as a result of the lens accommodating, thus making the image focus sharply on the retina. The treatment for farsightedness is spectacles with converging lenses (-glasses) which complement the refractive capacity of the lens, so that a sharp image strikes the retina, without the eye having to accommodate.

Astigmatism is often caused by the cornea being warped out of the normal spherical contour, with greater curvature along one meridian than another This means that two sharp images of an object are generated, only one of which lies on the retina; the second image lies in front of or behind the retina. Astigmatism is corrected by the use of spectacles with so-called cylindrical lenses.

The eyes are seldom alike as regards refractive power/refractive error. If the difference is 1 diopter or more, it may have an impact on visual development. This state is called anisometropia. Most often, the refraction is the same in both eyes, e.g. both eyes are far-sighted, but to a different extent (Karpe, 1972). In anisometropia, the retina of both eyes do not receive sharp images of an object at the same time. One can only see clearly with one eye at a time. Anisometropia thus reduces stereoscopic vision, and can cause strabismus and amblyopia.

Anisometropia is treated if amblyopia or strabismus can be diagnosed, or to prevent the development of these sight defects.

Refractive error means that the image on the retina is blurred and, as a result, the child's visual system does not develop normally. If there is only a refractive error, the treatment is spectacles, which give a sharp image on the retina, thus enabling normal visual development to take place. The refractive error can change during childhood, and the spectacles must of course be adjusted to this changes. Such changes occur regardless of whether the child uses spectacles or not.

Strabismus

Strabismus means that the eyes are not directed at the same time towards the same object. One eye fixates the object, the other does not. Normally, the optical visual axes of the eyes are parallel when the eyes focus on infinity. When the eye focuses on a closer object, the lens changes so that the image on the retina becomes sharp. At the same time the eyes are turned inwards and the optical axes form an angle. These two actions: changing the refractive power of the lens and changing the direction of the optical axis are always coupled in accommodation/convergence reflection.
Strabismus can occur in latent or manifest form. Both latent and manifest strabismus can be of three types, two horizontal and one vertical.

Horizontal strabismus is divided into *Outward strabismus:* One eye looks straight forward, the other "looks" outwards and *Inward strabismus:* One eye looks straight forward, the other "looks" inwards towards the nose.

Vertical strabismus means that one eye looks straight forward, the other "looks" upwards. This type of strabismus is uncommon.

Combinations of horizontal and vertical types of strabismus can often be found.

Furthermore, strabismus can be constantly one-sided, it always occurs in the same eye, or alternating, sometimes one eye is strabismic, sometimes the other.

The cause of strabismus

The exact cause of a child to beginning to squint is often unknown. Strabismus starting at a very early age, as early as the first month of life, is probably caused by some disturbance in the mobility of the eyes, or in the parts of the brain that control this mobility. Sometimes strabismus is combined with other changes in the function of the nervous system, but often it is the only disturbance. This form of strabismus is seldom hereditary, and children with this defect seldom suffer from a refractive error and spectacles seldom influence the degree of their strabismus. If there is any refractive error, spectacles must, however, be prescribed. If necessary, they can be worn from very young age. Strabismus usually occurs between the ages of 1 and 3 years, in which case it is a hereditary form of strabismus. A common cause of this type of strabismus is the refractive error called farsightedness (hypermetropia).

To be able to see clearly at a distance without spectacles, a child suffering from farsightedness must use its ability to focus close up (when accommodating, the eyes are turned a little inwards towards the root of the nose - they converge). Accommodation and convergence are always linked. Children begin to use their ability to accommodate more and more between the ages of 6 and 12 months, which is why this form of inward strabismus appears from this age.

The influence of strabismus on vision

If the eyes are directed straight forward, i.e. the optic axes are parallel when focusing on an object in the distance, the visual sensations from both eyes is combined into one image in the visual centre in the optical cortex. When the eye is strabismic, the image of the object looked at strikes different places on the retina in each eye and you see double. This is very unpleasant and, accordingly, the brain disconnects one image in order to avoid double vision.

In children with a plastic nervous system, the disconnecting process is very easy. One eye focuses on the object and the image from that eye is registered in the cerebral cortex, while the image from the strabismic eye is unconsciously suppressed and not perceived. This leads to a break-down in the co-ordination between the visual sensation of the eyes which, in turn, disrupts binocular vision and prevents depth perception.

The visual acuity in one eye which is constantly strabismic can also be so strong that the child sees badly with that eye if it functions alone without being negatively influenced by the other eye. A child who is strabismic in an eye , might therefore have poor detail vision in that eye, even when the other eye has been disconnected by means of an eye-patch. If the strabismus changes between the eyes, the brain also suppresses the double picture. However, constant changing from one eye to the other guarantees that both eyes are trained to focus and that neither of them is affected by visual defects through being disconnected by the brain and understimulated. (Asbyry & Burke, 1995).

Treatment of visual impairment

As mentioned above, the development of visual acuity continues until about seven years of age after which it ceases to develop. Treatment must therefore begin as early as possible.

Treatment begins by correcting all existing refractive errors with spectacles. In cases when the strabismus is caused by farsightedness, spectacles may sometimes be sufficient to correct the position of the eyes. Spectacles often only reduce the strabismus angle. If the strabismus cannot be corrected by means of spectacles, it is most important to train visual acuity. The strabismic eye, which has not been used before, is forced to focus by covering the sound eye. The degree of the visual defect determines the choice of either semi-transparent or non-transparent cover (occlusion) over the sound eye. In some cases, atropine drops in the sound eye are used, which dilates the pupils and paralyses the accommodation, thus reducing the visual acuity in this eye.

The duration of the treatment is shorter the younger the child is but is, of course, also influenced by the severity of the visual defect. A severe visual defect needs longer occlusion treatment than a minor one. It is estimated that about six months of treatment is necessary before it is possible to confirm a positive result of the treatment. When the visual acuity of the affected eye has increased, possibly to the normal level, maintenance treatment can begin. This treatment rarely needs to be so intensive and is thus not as demanding as the initial treatment.

During the treatment period, many of these children are clearly handicapped. The child is compelled to function at home as well as in the nursery school with the vision it has in its bad eye which, in the initial stages of the treatment can be very reduced. Children do not like having their eyes occluded so it is easy to understand that the child often refuses to wear a patch, and that many problems may arise (Kushner, 1991).

When visual acuity has improved and if the strabismus angle still is large, corrective treatment is possible in the form of an operation during which the position of the eye is changed by weakening or strengthening the action of the eye muscles. The action of a muscle can be weakened by cutting its attachment in the sclera and moving it backwards. The action of a muscle can be strengthened by cutting its attachment to the sclera and removing part of the muscle, i.e. shortening the muscle. From experience, it is known that the development of sight is not usually affected by a strabismus operation, but treatment of the defect must continue, even though the strabismus seems to be cured.

Chapter 5

Phenomenography as a research perspective

Phenomenography is a qualitative research approach which was developed by researchers at the University of Gothenburg in the early 1970s (Marton, 1981). Many of the Gothenburg studies were text-related analyses of the content of learning. The analysis searched for levels of understanding that students had reached after reading a text. The analyses further sought to account for the qualitative differences in understanding that were found in terms of the way in which the task had been approached by the students.

Marton and Säljö (1984) concluded:

> We had been looking for an answer to the question of why students had arrived at those qualitatively different ways of understanding the text as a whole. What we found was that *the students who did not get "the point" failed to do so simply because they were not looking for it.*
> The main difference we found in the process of learning concerned whether the students *focused on the text itself or on what the text was about; the author's intention, the main point, the conclusion to be drawn.* (p. 43).

Phenomenographic research investigates the qualitatively different ways in which people experience phenomena. The focus is on how people grasp the world, not on how the world is *per se.*

Marton and Säljö (ibid.) differentiates between two perspectives from which the world can be observed, the first and second order perspective. In the sciences, much of the research claims to describe the world "as it is"-*the first order perspective.* The phenomenographic studies focus on "reality as conceived", "how things are experienced" *-the second order perspective.*

Marton and Säljö (ibid.) says that a differentiation between the first and second order perspective

> ...has nothing to do with the metaphysical distinction between the real and the apparent, or with arguments for or against as to whether there is a reality as such that is accessible to us (p. 178)

According to Marton & Booth (1997):

> Phenomenography, when applied to the phenomena dealt with in established disciplines, thus focuses on the meanings on which knowledge about the different phenomena rests, especially in relation to meanings that those phenomena may have for the learner entering the respective fields of knowledge. The question of the taken-for-granted ways of experiencing phenomena is largely ignored within the research effort in fields that are stable; they are generally characterized by contemporaneous self-evident ways of seeing (p. 121).

Uljens (1989) points out that qualitative analysis in empirical research might be aimed towards the first as well as second order perspective. From this point of view, it follows that it is not interesting whether a comprehension is true or false - the interesting task is to describe how people comprehend or grasp something.

Strömdahl (1996) holds that the distinction between ´statement-about - reality´ and ´statement - about - perceived - reality´ indicates that there are two categorically different realities, on the one hand a 'directly accessible reality' on the other hand a 'perceived reality'. Strömdahl (ibid.) thinks, however, that we never get hold of reality, everything is 'perceived reality'. The difference between the first order and second order perspective is that in the first order perspective the researcher is *directed to the_world,* in the second order perspective the researcher is directed towards *ways of experiencing the world* Marton(1981) has illustrated this in the following way:

> In Educational Psychology questions are frequently asked about, for example, why some children succeed better than others in school. Any answer to this question is a statement about reality. An alternative is a question of the kind asked by Säljö (1981): What do people think about why some children succeed better than others in school? Any answer to this second kind of question is a statement about people's conception of reality... (p. 177 - 178)

This quotation shows the difference between the first and second order perspective as a difference regarding level of description.

Phenomenography (ibid.) is seen as a research approach (Larsson,1986;Hasselgren,1981),which means that phenomenography expresses recommendations about research territory, research method and level of description.

The choice of research level means a focus on the comprehended world, that is, how people comprehend phenomena in the world around them. The choice of research method means a qualitative analysis, often based on verbatim transcriptions of interviews, which leads to a description of qualitatively different conceptions of a phenomenon. The choice of level of description means that the content of understanding must be possible to identify in those categories constituting the result of the phenomenographical analysis (Larsson, 1986).

When Marton (1981) defines phenomenography, he stresses what phenomenography does not claim:

> The aim of the research programme argued for in this paper is not, however, to classify people, nor is it to compare groups, to explain, to predict, nor to make fair or unfair judgements of people. It is to find and systematize forms of thought in terms of which people interpret aspects of reality....It is research which aims at description, analysis, and understanding of experiences (p.180).

Within phenomenography, a distinction is made between the experience as a process and the experience as a phenomenon. The starting point is that content and structure are inseparable. From the perspective of phenomenography it is impossible to talk about experience without content. Phenomenographic research investigates the qualitatively different ways in which people experience various phenomena (Booth, 1992).

According to Marton (1986):

> Experience is always the experience of something and conceptualization is always the conceptualization of something (p.24).

People often take for granted that the reality we are living in can only be experienced in one way and that we are all experiencing it in the same way. However, there is no objective, entirely common reality. We experience phenomena in the world around us in more or less varied ways. Marton(1992) writes:

> An important thing about differences in our understanding of the world is that such differences are, in most cases, almost invisible. We are seldom aware that our understanding of a phenomenon does not match someone else's understanding. We are not even aware that we see the world in an individual way. We believe tacitly that we see the

> world as it is; without further reflection, we take it for granted that others see it exactly as we do (p. 254).

Phenomenography aims to describe the relation between man and the surrounding world. The way of experiencing something is an internal relationship between the individual who experiences and that which is experienced. Man tries to create meaning between himself and the world. To experience then means to create meaning, to be able to discriminate how a phenomenon is related to a whole. (Svensson, 1984).

A very frequently used quotation is from Marton & Svensson (1978):

> We try to describe how people experience phenomena or aspects of the surrounding world...Comprehension often stands for the implicit, that which cannot be told, as it has never been an object of reflection. Comprehension is that frame of reference where we collect our knowledge or the ground on which we build our reasoning (p. 20.) (My translation).

In the quotation above, the unreflective nature of conceptions is pointed out, something that Fallsberg (1991), among others, thinks is a little doubtful. Marton's statement might, however, be interpreted as meaning that those categories of thinking which constitute the result of a phenomenographic study are below the "linguistic level" and are thus very often found on a preconscious level.

Approaches to learning and outcomes thereof

Previously, many studies in research on learning used learning materials with a low degree of meaningfulness. The reason was to avoid distorting effects of previous knowledge. The aim of these experiments was to arrive at a description of the process of learning in general, but the outcome of learning was often just a description in quantitative terms (Dahlgren, 1997). The process of learning in itself was stressed - the content of learning was of minor importance. In an experimental situation, it is important to keep the learning task as neutral as possible, but the results of those experiments only show how students set about learning when the learning task has no meaning. Dahlgren (ibid.) comments on this as follows:

> ...most human learning depends on meaning and it is directed towards it. To learn is to strive for meaning, and to have learned something is to have grasped its meaning. (p. 27)

The qualitative approach to research on learning does not look at knowledge as marked pieces of knowledge which can be "poured" by the teacher into the learner and remain in exactly the same form. Interest is not focused on "how much is learned", but on "what is learned". Meaningful texts are used in the experiments. These texts could contain a description or an explanation of a phenomenon. The subjects are given such a text and are asked to read it carefully to be able to answer questions about its content. In this way it became possible to investigate "what is learned". The analysis of the answers of the subjects aimed to describe the essence of the conception of the facts that the questions had concerned. The result was a linguistic formulation of the content of an idea that an answer implied. Dahlgren (ibid.) writes:

> The aim of the analysis is to yield *descriptive categories* of the qualitative variation found in the empirical data. The process involves the reduction of unimportant dissimilarities, e.g. terminology or other superficial characteristics, and the integration and generalisation of important similarities, i.e. a specification of the core elements which make up the content and structure of a given category. (p. 28)

It is assumed that the categories are generalisable between individuals so that many individuals may have the same conception in similar situations; however, it is not certain that the same individual will have the same conception in another context.

The categories which stand for people's different variants of understanding (or levels of outcome) constitute *the outcome space* (Marton, 1974). This outcome space is, according to Uljens (1989), not infinite.

Marton (1976, 1975, 1974) has further demonstrated the fact that the categories of description of a phenomenon can, as a rule, be hierarchically ordered. Some categories of description can be seen as more advanced, more complex or more powerful than others. (Marton & Booth, 1997).

Frequently, it has appeared to be possible to identify more general structural differences in levels of outcomes, such as conclusion oriented, descriptive or mentioning. Sometimes, sets of outcome categories can represent hierarchies, where the levels of outcomes are related to each other based on their degree of specificity, inclusiveness or completeness (Dahlgren, 1997).

When using text reading, it has been found that qualitatively different ways of understanding a text correspond to qualitatively different ways of organising and approaching the material employed by the individual. It is further argued that changes in understanding of the meaning of the text are based on how something is structured but that this way of structuring implies changes in understanding. For a structure to be established, the components in a whole should be seen in relation to each other and the components be experienced as representing one and the same whole (Marton, 1986).

Phenomenographers also discriminate between structure and reference when it comes to the outcome of learning. The structural aspect concerns how the learning is organised, that is, how the various aspects of a phenomenon are considered and related to each other. The referential aspect concerns the learner's understanding of the meaning of a phenomenon. The outcome of learning can be described in sets of categories which can be differentiated in terms of their structural properties either in a *hierarchical* relationship, there some categories are more specified or elaborated than others or in a *horizontal* relationship which means that specific categories are equal in relation to each other because different aspects are focused on (Uljens, 1989). Any ranking must be carried out in relation to an external criterion.

Hence, there is a correspondence between the two aspects of learning outcomes and the two aspects of the act of learning. In the very process of learning a structural and referential aspect can be discerned. Svensson (1976) differentiates between an *atomistic* and a *holistic* approach to explain the *structural* aspect of the learning process. According to Svensson (ibid.), a holistic approach means that the focus is on the text as a whole and what the crucial idea of the text is, while an atomistic approach means a focus on details of the text, thereby neglecting the meaning of the text.

When it comes to the *referential* aspect of learning, Marton & Säljö (1976) differentiate between a *deep approach* and a *surface approach*. A deep approach means that the learner notices the meaning of the text, the author's purpose of the text ("what is signified"). A surface approach means that the focus of the learner is on details and not on the text as a whole. The terms surface approach and deep approach are therefore about the referential (what) aspect, while the terms holistic and atomistic are about the structural (how) aspect of the learning process.

Marton and Säljö (1976) have shown that the relationship between the students' approach and the level of understanding means that students who had a deep approach to learning had a more complete understanding and were also able to remember more factual details than the students who had a surface approach.

In phenomenography, learning is looked upon as a qualitative change of the learner's view of something in the surrounding world, not as a quantitative growth of the amount of facts.

This is something that phenomenographic and cognitive learning research have in common. The difference is that phenomenography does not assume that the learner has relatively stable learning strategies in his brain. Nor does it assume that there exist schedules that have their counterparts in an outer reality. If so, it would mean that there existed a dualism between man and the world around him, something that phenomenography repudiates (Uljens, 1989 ; Marton, 1987).

Marton and Ramsden (1988) write:

> Learning should be seen as a qualitative change in a person's way of seeing, experiencing, understanding, conceptualizing something in the real world - rather than as a quantitative change in the amount of knowledge someone possesses. It is logically impossible for learning defined in this way to be content- and context-free. Learning techniques and instructional strategies are inextricably linked to subject. (p. 271).

Learning is thus seen as a change in the individual-world relation. Svensson (1984) expresses this in the following way:

> Learning is not a change within the learner but between the learner and his surroundings. This is what we mean by relational view of learning. That learning is relational in the sense that it takes place through an interaction between the learner and the world around him is also to be found in the traditional understanding of what learning is. The relation is then seen as the person being affected in some sense with regard to behaviour, knowledge, or existence as a result of his interaction. Thus the relation is considered to have the direction from the external conditions leading to change in the person, which reveal themselves in continued interaction. We believe it to be more fruitful to consider the change as having directly to do with relation (between the

> person and) the world around (him). Interaction with external conditions thus leads to change in the person's relation with external conditions, and this change is what is considered to be learning. (Svensson, 1984, p.8, translation by Booth, 1992, p.53)

Learning as a change in understanding phenomena

Learning is often described as a change in conception - a qualitatively distinct shift from one conception to another (Dahlgren, 1997).

Through phenomenographic studies, it is possible to discover which qualitatively different structures and meaning a certain content of teaching have given rise to in connection with the goal of the teaching and learning. The goal then consists of the understanding or knowledge that corresponds to the currently existing scientific theory concerning the content of teaching (Kroksmark, 1987). Kroksmark (ibid.) holds the opinion that phenomenography takes sides with learning in a holistic meaning. This means that teaching should be directed towards comprehensive images rather than isolated facts. However, what often happens in teaching is that one learns the terminology in the field, a kind of denominational knowledge (Hansson-Schermann, 1994).

Marton (1980) writes:

> ...new ways of functioning and new ways of thinking must necessarily build on and modify or replace earlier ways of functioning and thinking (p. 9) (My translation)

Despite being aware of one's own experience, there is in all likelihood a pedagogical potential in being aware of alternative ways of experiencing the phenomenon. In fact, the two may be related in the sense that being aware of other ways of experiencing may facilitate the awareness of ones own way of experiencing (Dahlgren,1997). It might become necessary for somebody (a teacher, for instance) to challenge the learner's way of thinking in order to show that one conception is better than another. It seems to be important to design training in a way that brings about some sort of conflict of thoughts in the learner's mind. The learner must be given opportunities to confront his understanding and his values with alternative ways of thinking (Dahlgren & Vernersson, 1987).

Hansson-Schermann (1994) holds that the way to create a more qualitative change in the way of understanding in conjunction with training, as phenomenography suggests, is to:

- try to make the learners aware that there are different ways of understanding what has to be learned
- use the "new" visible conceptions of what should be learned in the training
- show the learner his own conceptions of what has to be learned
- try to explain that there are different conceptions of learning
- make the learner's own conceptions of learning visible
- use the "new" conceptions of learning in the training (p. 53) (My translation).

The role of the context of learning

When we experience an object or a situation, it always appears in a certain context which can be characterised as a socio-spatio-temporal location - a context, a time and a place. A phenomenon is, on the other hand, experienced as abstracted from or transcending such anchorage (Abrandt, 1997; Marton & Booth, 1997). Sometimes it is difficult to differentiate between our understanding of the situation and our understanding of the phenomena that lend meaning to the situation. The situation is understood in terms of the phenomena involved, but we are aware of the phenomena from the point of view of the particular situation. We cannot experience a phenomenon in the absence of a situation. In a research situation, we may, according to Marton & Booth (1997), opt to focus either on the situation or on the phenomenon "although they are inextricably intertwined in experience" (p. 83).

The difficult thing is that what is referred to as context in the research process is always selected from an organic totality of contexts. We can never account for the totality of context since, on a general level, everything is the context of everything else. According to Scharfstein (1989):

> If we assume that nothing can be understood outside its particular context, the same must be true of the doctrine itself, that nothing can be understood outside its context and the context of the doctrine must have *its* contexts; and so on (p.69).

Scharfstein(ibid.) claims that how one chooses context, depends on one's aim, which is never simply neutral.

The interviews in this study were carried through at the ophtalmological clinics at the hospitals. This is a well-known milieu for the parents and their children because it is there the children have been examined and the parents got information from ophtalmologists and orthoptists. In that way the interview takes place in a natural context for the parents and the patients.

Three kinds of phenomenography

In the phenomenographical research there are three lines of development. The first line of development was directed at the connection between peoples' conceptions of learning and their ways of studying. In this field, it was found that the way of setting about learning is not a stable trait but varies depending on the learning situation. Research on changes in conceptions through learning is also a branch within the field (Alexandersson,1985; Hasselgren,1981).

The second line of development has dealt with conceptions of central concepts within certain fields such as economics, where Dahlgren (1978), in a study of students' of Economics understanding of a number everyday economical phenomena, e.g. price, found that the categories of outcome not only constituted what was learned during the course, but also represented different and contrasting conceptions of the phenomena in the reality. Another example in the second field is a study by Lybeck (1981). He studied secondary school students' understanding of tasks requiring reasoning. Among other things, he identified two distinctly different ways of treating proportional calculations or conceptions of proportion. Renström (1988), who studied school pupils' conceptions of matter, can also be included in this line of development.

The third line of development in the field of phenomenographic research has been directed at descriptions of how people conceive of phenomena of a more general or a more specific nature. Theman (1983) investigated people's conceptions of political power. The main difference between the first two lines of development and the third, is that the first two focus on the relation between the conceptions, the conditions and the processes from which they derive, while the third focuses on the conceptions themselves as categories of description and the relations between these categories (Marton, 1988).

The phenomenographic approach in this study

This study is an example of the second category of phenomenography, where the research interest lies in learning as a result of being taught in an area where there is scientifically legitimate knowledge. When analysing the subject's understanding, there is a correct answer. And in accordance with this knowledge, it is also possible to place the given answers in hierarchical order. It is also possible that such hierarchical structures, once found, could be used to describe learning as a change from a lower to a higher level in the hierarchy.

In education and training, not least in institutional care, knowledge within certain subject matter areas or about a phenomenon is more or less taken for granted. The person who informs has to transfer his structure of knowledge bit by bit to the patient/learner. And after the information has been given, it is believed that the patient has acquired the knowledge in exactly the same form in which it was presented. Usually, this is not the case. Many studies (e.g. Wenestam, 1980) have shown that the outcome of learning might differ considerably between individuals. It is therefore very important to be able to describe what characterises patients' knowledge about their disease and its treatment, and in this way form a platform on which to arrange further information and on the basis of which to determine what the content of the information should be. The phenomenographic approach is valuable when it comes to understanding the effects of patients' understanding of phenomena in the case of amblyopia which are supposed to be necessary to support the treatment of the child.

In the present study, the area in focus is knowledge about amblyopia and its treatment. It seems reasonable to assume that this area of knowledge has a hierarchical structure, i.e. that there is an "ideal" structure of knowledge, defined by medical experts, which might be thought of as constituting a subset of the total outcome, which in turn consists of every conceivable structure of knowledge within this area. It is then of interest to study which structures of knowledge parents of children with amblyopia possess within this area. Moreover, the fact that it is of interest *per se*, might provide a starting point for arranging and carrying out patient training and patient information.

Data collection in a phenomenographical investigation

The interview is the principal method used in phenomenographic studies. It is classified as semi-structured and gives the researcher an opportunity to probe the individual's understanding by posing a number of predetermined questions which are thought to approach the phenomenon from a variety of directions and in this way increase the chances of a full exploration of understanding (Booth, 1992). Kroksmark (1987) has described the phenomenographic interview as an open method of questioning aiming at a deep understanding of the subjects' ways of thinking. This is explained by the position that the interviewer's task is to "reveal that which has hitherto been invisible or not explicitly thematised by the interviewee" (Kroksmark, 1987, p.264 in Booth, p.60, translated by Booth).

It is important that the interviewer encourages the subject to choose and develop his perspective of the phenomenon. This means that the interviewer both listens and asks more penetrating questions. The important thing for the interviewer is to go beyond a superficial level where the subject only says what can be expected.

According to Strömdahl (1996), the reason for a flexible and open-ended interview is the intention of uncovering the conceptions of the respondent and providing a substantial ground that covers the collective variations of conceptions.

Hansson-Scherman (1994) writes that the basis of the interview is the assumption

> - that people have different conceptions which might be conscious/reflected or unconscious/evident
> - there might be one or more existing scientific conceptions which the researcher in that case knows
> - that the researcher himself has a conception that is more or less conscious
> - that conceptions have a certain nature, which means that they are situation-bound, more or less stable over time, easy or difficult accessible. The last might have to do with how reflected or conscious the thinking is (p. 66) (My translation).

Marton & Booth (1997) emphasises the importance to make the articulation of the subject's reflections on experience as complete as possible. The interview takes place at two levels, on the one hand it is an interpersonal contact where the interview resembles a social discourse in structure and on the other, on a meta-level, the interview might be similar to a therapeutic discourse in that the interviewer tries to help the subject reflect previously unreflected themes. The interviewer tries to reach a meta-level through alternative questions, to bring the subject back to the focus of reflection or to confront the subject with earlier answers in the interview (ibid.). The degree of reflection required of the subject is, of course, due to the purpose of the interview.

Another aspect of an interview is the power balance between the interviewer and the subject. Theman (1983) discusses the importance of overcoming defences and the fact that an interviewer could easily destroy the relationship by pressing a subject too hard or not hard enough when it comes to the more reflective parts of the interview. The subject can deny the interviewer access to thoughts and reflections and even mislead.

Mishler (1986) argues against the traditional form of interview where the interview is looked upon as a stimulus - response situation, and where the context is unimportant. Mishler (ibid.) points to the uneven distribution of power between the interviewer and the interviewee. A shift in this distribution of power in favour of the interviewee gives him the opportunity to relate and by relating stories, express his understanding and experiences. The phenomenographic interview also aims at empowering the subject. Hansson-Scherman (1994) express this power with:

> ...can, wants and dares to tell how he experiences the phenomena and facts in question. (p. 67) (My translation).

The role of the interviewer

The interviewer in this study is also the author of this thesis. The author is not medically educated and there was thus a risk that the interviewer would not probe enough, that she would accept superficial answers, because she was not an expert on the subject matter. However, the interviewer has extensive experience of phenomenographic interviews in different areas as well as having followed the work at both clinics of ophthalmology, which were included in this study. Furthermore, she has participated in the theoretical sections about amblyopia within the framework of the medical educational programme. The interviewer has also participated in producing the learning material (booklet) for the parents in this study. This, together with following the usual methods of probing, means that the interviewer can be considered to have extracted as much as was possible from every interview.

In addition to the most common techniques of probing, such as nodding in agreement, agreeing with a "mm" and remaining silent after an answer when further elaboration was judged necessary, the probing strategies described by Abrandt (1997) were used, e.g. repeating. Repeating means that the interviewer repeats the last sentence of the subject's utterance in a questioning tone when the subjects answer is considered insufficient. A request for clarification is the next step, which means that the interviewer, for example, says: " Can you explain what you mean by that". If neither repeating nor a request for clarification elicits sufficient information, the next step is to ask for elaboration " can you tell me more about that". A fourth strategy for probing is a request for confirmation. This means that the interviewer summarises the subject's answer and asks if this is what the subject meant. The subject then has the option of either confirming or correcting in order to clarify the answer.

It was important that the interviewer did not judge the answer as being right or wrong since this might have influenced the subject's answers to subsequent questions in the interview.

The phenomenographic analysis

The focus in the phenomenographic analysis is on a collective level. Different conceptions are interesting foremost in comparison of other ways of comprehension. Changes in understanding are analysed on a collective level, i.e. how individuals move from one category to another. The reason why an individual expresses a certain understanding is not of primary interest in phenomenography. The reason is that understandings of individuals are assumed to be varying and context-dependent. It is assumed that variation of understandings that occurs in a certain population is so wide that even if the individual's understanding changes, it will not get outside the understandings which have already been surveyed. Consequently, it is interesting to describe the width of variation of the categories of description. In order to obtain knowledge about the range of variation in people's conceptions of a phenomenon, a fairly large number of individuals' conceptions of that phenomenon has to be compared. This, it is assumed, will make it possible to obtain a system of descriptive categories irrespective of whether an individual moves from one category to another. (Uljens,1989)

The phenomenographic view is that the ways of expressing one phenomenon in a particular society are limited (Marton, 1986), hence, each phenomenon has a limited outcome space. Another assumption is that a kind of saturation emerges when a certain number of individual's answers have been analysed. The aim of the phenomenographic analysis is to detect the variation in conceptions that exists in the material. Every single interview must be seen as a well-defined whole. It is often difficult to form an opinion about what the subjects mean if one tries to analyse single words or isolated responses. Often words and responses must be seen in relation to the other parts of the interview (Kroksmark, 1987).

Dahlgren(1989) has described the different steps in the phenomenographic analysis in the following way. The analysis starts with a careful reading of the transcribed interviews, individually and collectively. This is to enable the researcher to *acquaint himself with the material.* After this he selects statements for each question which are judged to express a certain conception of the phenomenon in question. The answers are marked, removed and collected in a separate file where all answers to a certain question are available for the further analysis. The next step, *the condensation,* consists of a search for the core of the answer in the statement. To find the core, the researcher must be prepared to switch his attention between the two contexts, the group of quotations to which the statement belongs and the interview from which it has been taken. After that, it is time for the next step, *comparison,* which means that different answers are compared with each other, and statements that seem to have similarities are compared to ascertain what they have in common. A number of groupings emerges and the researcher tries to *articulate* the preliminary category, i.e. he expresses linguistically what he found to be contextually equal to a certain group of answers. The next stage in the analysis is the *contrastive* phase, when the researcher reflects on whether there is a distinct difference between the groups of answers and whether the content of the conception corresponds to the name of the conception. The purpose of the contrastive phase is to guarantee that the categories will be complete and exclusive, i.e. all answers must be found in some category and the conception categories must differ from each other. This often implies a *reduction* in the number of categories. The result of the analysis is an outcome space where each category contains a common conception.

Credibility

A fundamental prerequisite of a scientific study is the credibility of the findings, what inferences can be drawn. To tackle these problems, the concepts of reliability and validity were early introduced in the quantitative research paradigm. Even if there still are some problems and controversy about the concepts, one can say that the concepts are comparatively well-established and accepted. Reliability, to begin with, is a complex concept. Usually, four components are referred to: consistency, accuracy, objectivity and stability. Attempts to use the concept of reliability in connection with qualitative studies have been made. Strömdahl (1996) uses the term inter-rater reliability, which "...reflects how precise the categories fit or communicate conceptions expressed by the respondent"(p.46). Co-judge reliability is a concept discussed by Szlarski (1996) Uljens (1989) and Larsson (1986).

However, using the concept of reliability within the qualitative and phenomenographic paradigm leads to problems. The problem is, for instance, illustrated when Uljens (1989) thinks that an alternative to reliability is to speak of different degrees of validity. Alexandersson (1994), for instance, questions whether a co-judge would put the same meaning into the categories as the researcher. The task for a judge from outside will be to control the degree to which an established system of categories corresponds with the researcher's interpretation of the interviews. Trost (1997) points out that when using qualitative interviews, stability is not as important as in a quantitative study. Changes are exactly what are of interest in the qualitative study. Furthermore, the phenomenographic interview presupposes a low grade of standardisation, which is contrary to the quantitative view. Trost (ibid.) says, that to him it is strange to talk of reliability when using qualitative interviews.

Another procedure which often replaces the inter-judge reliability test is called 'negotiated consensus'. This process means that several investigators, often experts, have been involved in the analysis and their suggestions about categorisation are discussed, frequently in several rounds, until agreement is reached about the final categorisations. (Wahlström et al, 1997).

In the quantitative research paradigm, validity can be expressed as Kerlinger (1973) puts it:

> ...are we measuring what we think we are measuring. (p. 457)

It is a question of the validity of the *measurement*. In qualitative research, one aims at the *interpretation* (as the process and result) of the material which represents reality.

In quantitative research, which often involves testing hypotheses, the question of validity is about whether the researcher has managed to characterise the problem in such a way that the phenomena involved are measured according to intentions. In qualitative research, which often has an exploratory aim, less structured collection methods of data are used, because of the researcher's wish to be able to consider unknown factors.

Booth (1992), tries to elaborate the validity concept within the field of phenomenography by using terms such as *content related validity, methodological validity* and *communicative validity*. Larsson (1986) regards the use of co-judges, when defining categories, as a matter of validity.

Using the validity concept within the qualitative research paradigm is, however, problematic. Kirk & Miller (1986) think that qualitative research should put a different meaning to the concepts of validity and reliability because the qualitative paradigm has other assumptions about reality. Agar(1986), Guba(1981) and Merriam(1995) are of the opinion that standards by which quantitative studies are judged are inappropriate when judging the value of qualitative studies. Guba(1981) suggests naming the concepts differently. Internal validity would be replaced by value of truth and external validity by stability. Trost (1997) goes as far as to say that to quantitatively try to measure reliability and validity in qualitative studies is out of place.

However, interviews and other ways of collecting information about a problem must be carried out in an adequate way even within the qualitative paradigm and its phenomenographic sphere. Glaser and Strauss (1967) speak about credibility, and Trost (1997) holds that credibility is the main problem when it comes to qualitative studies and qualitative interviews.

In phenomenographic research, category is one of the core concepts. Fundamental to Booth's (1992) communicative validity, is how understandable the description of the categories are, otherwise it is not possible to judge the reasoning of the researcher. Giorgi (1975) writes that a fundamental requirement is that the reader must be able to "...see what the researcher saw, whether or not he agrees with it" (p. 97).

Marton (1981) discusses the question of whether another researcher will find the same categories in the data, that is, if replicability is possible, and claims:

> The original finding of the categories of description is a form of discovery, and discoveries do not have to be replicable. On the other hand once the categories have been found, it must be possible to reach a high degree of intersubjective agreement concerning their presence or absence if other researcher are able to use them (p. 148)

What Booth (1992), Giorgi (1975) and Marton(1981) are aiming at is reproducibility of categories, and reproducibility is, among other criteria, according to Gortner and Schultz (1988), a criterion of good scientific research.

In this context we would rather refer to the ideas expressed by Strauss and Corbin (1998), that the crucial question is whether the categories as well as methods of classification contribute to the credibility of the research. In this study, five investigators have been involved in the analysis - three physicians and two educational psychologists. One of the physicians had the main responsibility for judging the hierarchical order between the categories of conceptions. In most cases, the final categorisation was used as a framework for reassessment of the original interview material according to the description. As mentioned earlier, this last part often replaces the inter-judgement reliability test which has often been used in phenomenographic research.

Chapter 6

Method and research procedure

To be able to study which factors are important in an application of prescribed treatment, it must be possible to state with certainty whether a patient has adhered to the treatment or not. This means that, at least during an initial period, the researcher should restrict himself to diseases/injuries where there is a clear connection between the implementation of a treatment and improvement in the state of ill-health. At the same time, the absence of treatment must result in an unaltered or deteriorated state of ill-health.

In the ideal case, there are also objective criteria of change in the status of illness. In addition to which disease/injuries are chosen as the object of inquiry, it ought to be possible to define two distinct groups - patients who adhere to and do not adhere to the treatment – and study whether and how these groups differ.

The problem posed above also requires extensive studies of different diseases with different degrees of severity and different amounts of treatment, as well as different types of patients.

However, if one accepts a limitation in generalisation, there are some alternatives, for example:

1. Examination of patients with *the same disease and uniform treatment.* The aim here is to study whether different characteristics of compliance in patients are of any importance in the application of the prescribed treatment. Here, it is only possible to generalise the results to the specific type of illness.
2. Examination of some *different diseases* where the *treatment* has about the same intensity, i.e. encroaches to the same degree on the individual's normal way of life. In such a case, it is possible to make generalisations to diseases where the treatment has a similar intensity.
3. Examination of some *different diseases where treatment differs as to extent.* This offers the greatest potential for generalisation of the three alternatives, but there are difficulties in finding a number of diseases where there is a strong connection between application of prescribed treatment and objective criteria of a distinct improvement in the disease.

In the first phase, it seems most appropriate to use the first alternative, i.e. to study patients with the *same disease/injury* and *uniform treatment.*

The disease chosen in this study is amblyopia in children. What is unique is that here there is a *clearly measurable connection between well effected treatment and observed medical effect,* i.e. improved sharpness of vision, at the same time as absence of treatment results in an unchanged or deteriorating state of illness. This disease therefore satisfies the demand for an objective criterion of change in the status of illness. There is a clear connection between completed treatment and improvements in the state of illness. Thus it is possible to distinguish patients who apply prescribed treatment from patients who do not.

Design, participants and procedures

The main body of study was carried out during the years 1985 - 1990. The collection of medical information (e.g. the sharpness of vision of the subjects) continued until 1990.

The study was performed at the ophtalmological clinics at Sabbatsberg and Danderyd hospitals in Stockholm. The reason for locating the project at these clinics was that they are specialised amblyopic clinics. They provided access to an unusually large population of patients. Furthermore, the personnel had considerable medical knowledge of this type of ophtalmological handicap, and an awareness of and a great interest in improving the conditions for the patients through information and motivating the patients and the parents in favour of the treatment.

The study involved a total of 119 parents of children with amblyopia due to strabismus and/or refractive errors. It was stipulated that the children must not have any additional handicap as this might make comparisons difficult. The group represented a consecutive material of patients attending either of the two departments of paediatric ophthalmology in Stockholm. The reason for not using a random assignment rests on the assumption that it would be difficult for the nursery staff, after training, to treat the control group and experimental group differently. The overall design of the study is illustrated by the flow chart in figure 2.

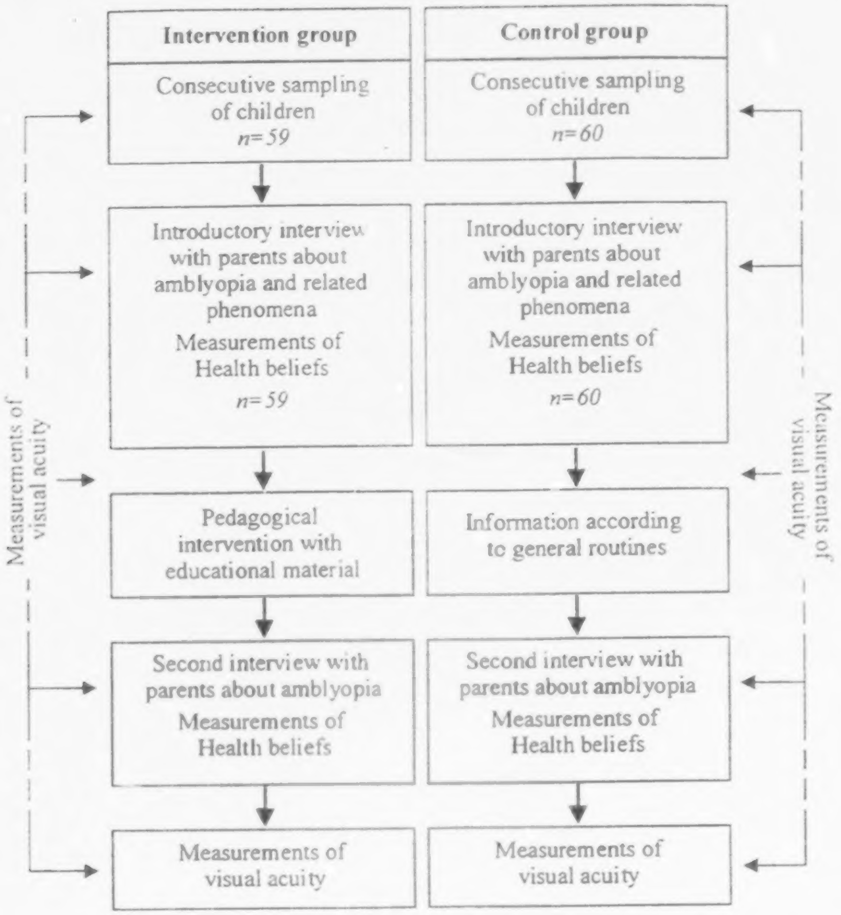

Intervention group
Control group
Consecutive sampling of children n=59
Consecutive sampling of children n=60
Introductory interview with parents about amblyopia and related phenomena
Measurements of Health beliefs
n=59
Introductory interview with parents about amblyopia and related phenomena
Measurements of Health beliefs
n=60
Pedagogical intervention with educational material
Information according to general routines
Second interview with parents about amblyopia
Measurements of Health beliefs
Second interview with parents about amblyopia
Measurements of Health beliefs
Measurements of visual acuity
Measurements of visual acuity
Measurements of visual acuity
Measurements of visual acuity

Figure 2. Design and measure of the study

The control group comprised 60 parents of children attending the clinics during the period January 1 - June 30, 1985, and the experimental group comprised 59 parents attending the clinics from September 1, 1986, to March 1, 1987. In this way, it was supposed to avoid any systematic influence of differences in treatment traditions between the clinics. The reason for one person fewer in the experimental group was that one parent refused to participate in the study.

The patients were quite young with a mean age of 3 years and 6 months in the control group (median age 4 years and 1 month, range 5 months - 6 years and 9 months; seven children were over 6 years old) and the mean in the experimental group was 3 years and 9 months (median age 3 years and 8 months, range 5 months - 6 years 5 months; six children were over 6 years old). The period treatment of this group varied between 6 months to 1 year, depending on the child's age. The selection criterion was based on the cause of the visual defect and were determined by medical experts. Since the children were quite young, the parents were responsible for the contacts with the clinic as well as for managing the prescribed treatment.

About one month after confirmed diagnosis, and when the parents had some experience of the treatment an Introductory interview (see appendix 1) was held with the parent who considered him/herself to have most to do with the child. The interview, which was semi-structured, included the parents conceptions of amblyopia, strabismus and the treatment. The interview also included questions about the parents attitudes towards the disease and its treatment. At the same time, the attitude measurement, the Health Belief Model (see appendix 2), was administered.

After an interval of 6 - 8 months, all the parents went through the second interview in order to establish possible changes in attitudes towards and conceptions of the disease and its treatment. The second interview included the same domains as the introductary interview. The Health Belief Model was also used in this post-test.

The children were clinically examined, primarily through an assessment of their visual functions, at regular intervals determined by the clinic. Thus, the investigation can be characterised as a methodological triangulation comprising both medical and instructional treatment as the independent variable, and clinical as well as psychological measures of the dependent variable.

After about 10 months (when the last patient in the control group had been treated for about 6 months), the nursing staff – ophtalmologists and orthoptists at both clinics – attended as mentioned before a training course on learning and didactics. The aim of the course was to teach the medical staff how to brief and inform patients/parents about the disease and its treatment. Further the object of the course was to produce the experimental group's learning material, the booklet. This booklet was then used by the staff when the parents from the experimental group visited the clinics during the treatment. The control group was instructed in the traditional way according to the normal routines at the two clinics.

The experimental group and the educational program

It was considered important to provide conditions for the parents in the experimental group to achieve as thorough as possible understanding of the illness and its treatment. When designing the education program it was thus important to consider such factors that could enhance an understanding of visual development and the amblyopia phenomena. Strategies allowing interaction with the learner is important according to Eggen & Kauchak (1988). Consequently, it was essential to design a learning situation where the physician and the orthoptist could assist the parents to study the booklet. The nursing staff was instructed to give information about the illness and its treatment at the patient's visit to the clinic. Between these visits, the parents were asked to study the booklet and prepare questions for the nursing staff at their next visit. Thus, the intention was to bring about intensified activity on the part of the parents when studying the booklet, which is essential in meaningful learning (Dahlgren, 1975). It comprised the following parts: The anatomy of the eye, development of vision, normal vision, refractive errors, strabismus, amblyopia, binocular vision, a description of the examination and methods of treatment. In addition, there was space for noting the individual child's vision test values and prescribed treatment, the names of the physician and the orthoptist, etc. The purpose of this latter part was to provide frequent feed-back to parents regarding the progress of the treatment.

Data collection

Conceptions of amblyopia and its treatment

The study of the parents' knowledge. i.e. their conceptions of the disease and its treatment, took the form of interviews (the introductary and the second interview). All interviews were carried out at the ophtalmological clinic to which the subjects belonged. When a patient, with an adequate diagnosis for this study, came to the clinic, the reception personnel asked the parents whether they were interested in participating in the study. The parents themselves had to decide which parent had most contact with the child. This parent was interviewed in conjunction with the visit at the clinic. All parents who took part in the study were interviewed twice. The first time was at the beginning of the treatment (after about three or four weeks, when they had some experience of the treatment) and a second time after about six to eight months of treatment.

15 questions about the disease and its treatment were asked. The domains dealt with were, development of normal vision, refractive errors, strabismus, binocular vision, reasons for the character of treatment, reasons for early onset of treatment and age related to onset of treating, surgical treatment and effects thereof, duration of treatment, effects of vision impairment, effects of strabismus on vision and consequences of interrupting treatment.

The average length of the interviews was 65 minutes.

A phenomenographic analysis was performed on the transcribed material in order to find conceptions of meaning, effects and treatment of amblyopia. The changes in the parents' way of conceiving these phenomena between the two interviews were also analysed quantitatively. The distribution of subjects over the categories in both groups on the two interview occasions are shown and discussed.

The questions designed to measure the knowledge of the parents were chosen by the author of the thesis and three ophtalmological experts. To ensure the relevance of the questions, the selection criterion was these three medical experts opinion of what knowledge was important for the parents to know.

Attitudes toward the disease and its treatment

Health beliefs were measured by the Health Belief Model, which is a model focusing on the patient and his relatives as decision-makers (see, for example, Becker et al, 1974). Becker et al (ibid.) think that the probability of compliance with a patient/relative is dependent on an objective and logical thought process, where patients/relatives weight the experienced benefits of compliance.

The Health Belief Model is a standardised scale and may be regarded as an indirect measure of patient compliance, or rather the potential for compliance. It yields a value which indicates the level of motivation for treatment in a person

The model with its variables is very well known, thoroughly tested and widely accepted (see, for example, Bates et al. 1994; Janz & Becker, 1984).

It was therefore judged that only an adjustment of the items was required for the needs of the present study. The starting point of this adjustment was items used for studying health beliefs of diabetic children (Richt et al, 1983). These items were "translated" into terms suitable for amblyopia. Then the questions were tried out on a pilot group. This group consisted of 30 parents of children with the same diagnosis as the members of the experimental an control groups. This test was carried out before the start of the main study and the intention was to find out how adequate the questions were.

The introductory and the second interview also contained 16 questions about attitudes towards the treatment and experiences of the treatment (shown in connection with the supplementary analysis).

Health beliefs were measured with 43 items in a questionnaire. Health Motivation with 16 items, Value of Reducing the Threat with 12 items and Probability of Reducing the Threat with 15 items. A Likert-type scale was used with the end points "totally agree" and "totally disagree".

Measurement of visual acuity

According to Rydberg (1998), visual acuity is defined as a measure of visual resolution, that is, the capacity to discriminate details with high contrast.

According to Rydberg (ibid) there are three subtypes of visual acuity testing in young children according to the type of stimulus used.

1. detection acuity - the stimulus should be detected from the background
2. resolution acuity - the stimulus pattern, usually a black and white grating, should be resolved
3. recognition acuity - a letter or a symbol should be recognised by the subject and identified by matching or naming.

Here, the usual letter acuity charts with lines of letters are to be found. Each line contains letters of a certain size, graded in tenths of normal visual acuity. In the case of most of the charts, it is estimated that the bottom line should be possible to read at a distance of five metres for a person with normal visual acuity.

Visual acuity can also be expressed as a quota d/D, where d is the distance where the line in reality has been read. The D is the distance from which an eye with normal visual acuity can read the line. This way of describing characterises Snellen-type charts. The test distance is usually six metres (Karpe, 1972).

When it comes to small children, it is not possible to use letter acuity charts. Instead, different figures, such as hands, hooks or rings can be used. Another example is the HVOT test, where a letter acuity chart with the letters HVOT is used. The child has a picture book with the letters HVOT. The child then has to compare the letters in the picture book with the letters the tester points to on his chart. Here, the test distance is three meters.

For the HVOT test, the criteria were to identify 4 out of 4, 5 out of 6 and 6 out of 8 letters correctly.

According to Schapero (1971) amblyopia is, in terms of visual function, defined as a difference of two or more lines in visual acuity between the amblyopic eye and the non- amblyopic eye

In studies of amblyopia it is normal for an increase in visual acuity, shown as two lines on a letter acuity chart, to be counted as a marked increase.

Subjective visual acuity testing requires the active participation of the child. The results depend to a great extent on the child's ability to understand instructions and do the test, e.g. identify, name or point, compare and match.

In the present study, the measurement of visual acuity was carried out by ophtalmologists and orthoptists at the respective ophtalmological clinics using test methods appropriate for the age of the children. The values were then transformed to Snellen equivalents. The test interval varied with the age (The clinic's normal routines were used).

Measurement of visual acuity is sufficient to deciding whether a patient has been compliant or not. The analysis of visual acuity improvement includes the changes over time in absolute values and as a percentage of the previous value for each individual. Values for the non-amblyopic eye are used as a measure of normal development. The visual acuity results were obtained approximately 18 months after the start of the treatment and was measured as absolute acuity of each eye, the percentage increase in acuity, and the ratio of acuity in the amblyopic/non-amblyopic eye.

Ophtalmologists are of the opinion that to achieve a positive result in terms of improved visual acuity, at least six months of treatment is required. Thereafter further treatment is required to obtain normal visual acuity. This is the reason why visual acuity was used as criterion of compliance after 18 months.

Chapter 7

Conceptions of meaning, effects and treatment of amblyopia

A description of the parents understanding of amblyopia and amblyopia related phenomena

In this chapter, the results of the phenomenographic interview is presented. The interview focused on the conceptions about the disease amblyopia and its treatment expressed by the parents of the amblyopic children.

First, the categories are introduced together with some examples from the interviews. This is followed by a discussion of the essence of the categories and by the distribution of subjects over the categories, experimental condition and pre- and post test.

First domain

1 The first domain to be dealt with is the meaning of *refractive errors*. This is a general question and does not refer to any particular kind of refractive error.

Five different conceptions can be discerned:

A. The light is refracted in front of or behind the retina.
The following quotation is an example of the category:

> The beam strikes either behind or in front, not where it should strike
> (N.B. Beam refers to a beam of light)

B. The light is spread too much or too little.

An example of this category is:

> Error of refraction means that it spreads too much or too little

C. The light turns around/is reflected/too far behind or infront of the retina/.

Here is an example of this category:

> The light turns either too far back or too far forwards.

D. One has difficulties in seeing at a distance or close up.

This quotation illustrates the category:

> You find it difficult to see things far away and close up

E. Refraction defects depend on lack of binocular vision.

The following quotation is an example of the category:

> One's eyes don't collaborate

In categories A-C there are often uncertainties about what is refracted or reflected. Some mention light explicitly but there are also references to "the picture" without any further elaboration of the concept. The retina is likewise not always mentioned in the answers. Some subjects talk about "the right spot" and some about "the back wall of the eye". The A category nevertheless indicates a correct understanding of the meaning of refraction defects. Some of the answers contain an additional part about the necessity of correcting the defect with some kind of lens in front of the eye.

B answers are more general and thus more diffuse than A answers in that they do not make any references regarding the refraction properties of the eye. Even if not directly erroneous, they are so general that they do not convey any understanding of the phenomenon. The C group of answers are unrealistic in that they are essentially based on the metaphor of the eye as a mirror. (Even if the eye is sometimes referred to as the "mirror of the soul", the conception of the eye as a reflector of light is fundamentally wrong). The D conception is basically a restatement answer, i. e. the answers in this group do not go beyond the mere manifestations of refraction defects. In a way, it can be claimed that this kind of answer is satisfactory, since basically nothing more than the meaning of refraction is asked for. From the probing that follows the entry question into the domain it is, however, evident that the subjects were incapable of elaborating the answers up to a level of causal explanation. The E answers definitely express a misconception since the existence or lack of binocular vision is not directly related to refraction defects. In a way, it is, however, understandable that the parents in the investigation group are so occupied with the phenomenon of strabismus that they associate any vision-related concept to it.

Second domain

2. The second main question deals with the *effects of strabismus* on vision, i.e. disrupted binocular vision and amblyopia. Four categories of meaning are required to describe the qualitative variation among the answers:

A. One eye dominates and the other eye gradually ceases to function. Binocular and stereoscopic vision deteriorate.

This can be exemplified by the following answer:

> Squinting means that one eye dominates and the other gives up. Stereoscopic vision disappears and so does depth perception.

B. Stereoscopic and/or binocular vision gradually disappear.

A typical answer in this category is:

> Both stereoscopic vision and depth perception disappear.

C. Vision gradually deteriorates whereby stereoscopic vision is affected.

An example of an answer in this category is:

> Squinting means that you see worse and if you see worse, depth perception is affected.

D. The eyes see different things, i. e. a kind of 'stereo effect'.

A quotation in this category is:

> If you squint, your eyes see different things and that means that you get a stereo effect.

Even if no category fully describes the course of events whereby the strabismic patient gradually loses vision in one of his/her eyes, the A-category comes quite close. Strabismus means that the two eyes see different things. This does not, however, lead to the kind of stereo effect mentioned in the D category, but means that the patient experiences double vision; a state that is so distressing to the brain that vision in one of the eyes is suppressed. This is the mechanism that results in loss of vision in the strabismic eye. The B category of answers is, in this respect, less causally oriented towards amblyopia and simply means that strabismus affects stereoscopic and/or binocular vision. C answers indicate that the effects on stereoscopic vision stem from a deterioration of vision in general as strabismus affects both eyes. The D category, as has already been mentioned, contains a correct statement in the first part of the answer, but the conclusion that this leads to stereoscopic vision is not correct. There is, however, a source of error here in that the meaning of "a kind of stereo effect" is not possible to determine from the answer.

Third domain

3. The third question deals with the conditions for the *development of normal vision*. There are four different categories of answers:
An example of this category is:

A. The development of vision is dependent on stimulation.

> The child must be allowed to see things, things which have different colours and things that move...follow them with its eyes.

B. The development of vision is dependent on training.

This is an example:

> The child must be allowed to train its vision, it's vision must be developed.

C. The development of vision is a question of maturation.

A typical answer is:

> It's a question of a process of maturity. The child can't receive (visual) impressions until this ability has matured.

D. The development of vision is dependent on training the eye muscles

The following quotation is an example of this category:

> The eye muscles must be exercised, they haven't been used properly before.

The distinction between A and B answers may appear to be very subtle but if it is emphasised that A answers focus on what happens in the patient's environment, i. e. the richness of visual stimuli, the essence of an A answer may be easier to understand. B answers somewhat stress the active role of the individual. C answers simply state that normal vision is a phenomenon dependent on maturation. Some of the answers in this category do, however, stress the active role of the patient as a supplementary condition. D answers more clearly indicate a misunderstanding, since they explicitly emphasise the importance of the topological position of the eye, although this is understandable in parents of strabismic children.

The following seven questions all concern the nature of amblyopia, refractive errors and strabismus and the effects of treatment.

Fourth domain

4. The first of these deals with the *reasons for treatment with occlusion of the eye and with glasses*. There are five different kinds of answers to this question:

A. Glasses are mainly needed for the refractive error, occlusion mainly for the treatment of the strabismus.

This quotation illustrates the category:

> Spectacles are for impaired vision, people who squint get a patch. If you see well, a patch is only needed so you can train away the squint.

B. They are different ways of treating the same thing.

Here, an example of this category:

> Different methods are used.

C. Occlusion is for the treatment of the refraction defect.

An example is:

> If you have an error of refraction, you put on a patch.

D. Occlusion is used if vision is good in one eye but poor in the other.

A typical answer for this category is:

> You give it a patch if it has good vision in one eye, but bad in the other, otherwise the child would shut it off more and more.

E. The magnitude of the strabismus determines the choice of treatment.

The following quotation is an example:

> It's connected with squinting, but I don't really know whether a large squint means a patch and small spectacles or the other way round.

The essence of the A answers - which also distinguishes them from the others - is that they imply that there might be two problems involved in many cases; strabismus and refractive errors, both leading to the visual defect of amblyopia. Subjects who have understood this fact also know that the two kinds of treatment have different targets. Lack of this insight is common to all other answers. B answers are most typical of the lack of this distinction. C answers represent a complete misunderstanding, since occlusion is not at all related to the refraction defect. The E answers are even more erroneous since they indicate the notion that treatment with a patch and glasses, respectively, are synonymous but chosen according to the amount of misalignment of the eyes.

Fifth domain

5. The second question in this section of the interview is about the *reasons for an early onset of the treatment.* Three different kinds of answers were found:

A. Vision can only be influenced during a certain period.

Here, an example:

> The development of vision can only be influenced before the age of 7 - 8, when there's time to do something about vision if something's wrong, after that it's too late to do anything about it.

B. The chances of normal development are greater the earlier the treatment starts.

A quotation which is typical is:

> There's a better chance of it being normal if you start early.

C. A young child is easier to control.

An answer from this category is:

> When children are small, it's easier to check that they are wearing the patch; when they start school, you can't check up on them in the same way.

The A answers are indicative of the existence of critical periods in the development of various abilities. This is also in all likelihood true of the treatment of amblyopia. B answers reveal the belief that early treatment is to be preferred in all cases of illness. C answers are more practically oriented towards the possibilities of successful management of the treatment.

Sixth domain

6. The next question is about the reasons for *surgical treatment of strabismus*. Two categories of answers are obtained:

A 1. Surgery is used as a method of treating strabismus.

An example is:

> If a patch is not enough...operation is effective when development is most intensive.

A2. Surgery is merely cosmetic treatment.

Here, a quotation:

> It's a question of appearance, you shorten the eye muscles so the eye looks straight.

There is a problem involved in the determination of which of these answers is superior to the others, since it is the nature of the strabismus that determines what is a correct answer. In many cases of divergent strabismus, binocular vision may be intact for close-up vision whereas it is lost for distance vision. The aim of surgery in divergent strabismus is to induce eye alignment and binocular vision also for distance. In cases of inward strabismus, the reasons for the operation are to a large extent cosmetic since normal binocular vision normally cannot be achieved. Depending on what kind of strabismus the respondents are referring to, both answers are thus correct.

Seventh domain

7. Closely linked to this question is the next one about *whether binocular vision improves after the surgery*. Here, two different kinds of answers are found:

A. Surgery is performed to improve binocular vision or for cosmetic reasons , and visual acuity is not affected.

A typical answer from this category is:

> No, there are mainly cosmetic reasons for the operation, depth perception might get a bit better but you still won't avoid wearing spectacles because it has nothing to do with vision, astigmatism and that sort of thing are still there.

B. Vision may be marginally affected, but this is not the reason for the surgery.

> Maybe a little bit, but the main reason for the operation is to make the eye look straight.

Eighth domain

8. A further question which is also related to the effects of surgery is whether the patient is *able to avoid wearing glasses after surgery.* The answers belong to any of three categories:

A. Surgery has some effects on vision impairment, but not on the refractive error.

A quotation typical for the category is:

> No, it's cosmetic. Of course you see a bit better if your eyes are set straight, but short-sightedness and astigmatism and those sorts of visual problems don't disappear

B. Vision is not affected by surgery.

A quotation typical for the category is:

> No, it (vision) is not connected with the operation.

C. Surgery leads to a temporary improvement of vision.

Here, an example:

> Yes, for a time they (the children) would avoid having to wear spectacles - but they'll need them (spectacles) later.

A correct answer to this question would be that binocular vision is affected by surgery, whereas sharpness of vision is not. This means that A answers reveal a deeper understanding of the phenomenon than do B answers, whereas C answers indicate a lack of understanding of why surgery is performed on the patients.

Ninth domain

9. The next question is about determinants of the *duration of the treatment.* There are three kinds of answers:

A. The duration depends on the development, i. e. the improvement, of vision.

An example of an answer in this category is:

> If he continues to make progress, it (the treatment) can be gradually reduced. When he reaches school age, he may only need spectacles for reading, but that's what the examinations (of his eyes) will show.

B. The duration is related to the chronological age of the patient.

This quotation illustrates the category:

> It's extra important for the treatment to continue until the age of 8 - 9.

C. A combination of A and B.

Here, a quotation:

> It depends on the results, but I think until about the age of 8.

A answers are more correct than the others. The B answers do, however, reveal some understanding since acuity does really improve as a function of age up to a certain age. C answers, also indicate a certain kind of understanding but are not entirely correct.

Tenth domain

10. Another question is about the effects of an onset of the treatment around the *age of three or at the age of fifteen.* The answers fall into two different categories:

A. Somatic reasons make it easier to treat a child at the age of three rather than when it is a teenager.

Here, an example of an answer in this category:

> The eye only grows until about the age of 8, after that vision can't be influenced.

B. Practical reasons make it easier to treat a child of three than a teenager.

An example of an answer in this category:

> It's more difficult to get a teenager to wear glasses, because then they don't want to admit that they see badly. It's easier to control a small child.

Eleventh domain

11. These categories also appear in the answers to the next question about *negative short-term effects* of vision impairment.

A typical answer in this category is:

A. Practical consequences of the treatment.

> Glasses need to be polished and then they need to be repaired fairly often because when X (the child's name) is playing, things can get a bit wild and then they do get broken.

B. Somatic consequences of the handicap.

An example is:

> They can get headaches and perhaps see worse and they could find it difficult to do gymnastics since they don't have depth perception.

In the first category, reasons such as mending the glasses are normally mentioned. In the second, there is an emphasis on situations where good vision is of importance such as when reading or recognising familiar persons.

Twelfth domain

12. In response to the question about *which eye is covered in occlusion* treatment, all the subjects said that the "best" eye is covered. A closely related question is why the "best" eye is covered. Here, all the subjects stress the training aspect, i. e. the "sick" eye should be trained.

> The best eye is covered, otherwise they (the children) would use it and it's not the one that has to be trained.

Thirteenth domain

13. A central question concerns *how strabismus affects vision.* Here, three different categories of answers are found:
An example of this category is:

A. Strabismus reduces binocular vision.

> Squinting affects depth of perception and makes it disappear.

B. Strabismus affects the refraction.

Here, an example:

> Things seem blurred from a distance, but working with things up close is all right.

C. Strabismus has a general effect on vision.

An example from this category is:

> Yes, you see worse, generally speaking

The A answers are obviously correct whereas the B answers - in many cases stating that close-up vision is unaffected - are not. C answers do not make any distinction as to the nature of the impairment but only state that vision is affected.

Fourteenth domain

14. Of great importance is also the question about *consequences of interruptions* of the treatment. Three distinctly different conceptions can be discerned:

A. Visual acuity will deteriorate.
An example of this category is:

> Vision would gradually get worse.

B. There will be a regression of vision to the state before the treatment.

A typical example of this category is:

> You'd have to start all over again so that your vision returns to what it was from the beginning.

C. There will be a stagnation in the development of vision.

A quotation is:

> Your vision would stop where it was, in other words, where it had got to after you'd been getting treatment for some time... I don't think it will get better by itself.

One may assume that the opinion expressed by the parents is of great importance not the least for their compliance with the treatment recommendations. The A conception, as well as the C conception, would in all likelihood lead to a higher degree of compliance. The B conception probably invites interruptions to the treatment. However, in the analysis we have placed B higher up in the hierarchy of categories of answers, since it is a better description of what is actually happening.

Fifteenth domain

15. In another question, the parents were asked about the *consequences of interrupting the treatment* for a month. Three kinds of answers are found:

A. A deterioration occurs, but it is reversible.

A quotation from this category is:

> Your vision could possibly get worse at first, but if you continue just a bit longer (with the treatment) it probably doesn't matter.

B. It affects the final result.

An example is:

> One's vision gets worse and it's important when it comes to what the final result will be. If you compare it with physical

> exercise, where you have to exercise continuously, so if you take a break for a month or so, you don't perform as well later.

C. It has no significance as regards the final result.

Here, an example is:

> It can't be important, you'd probably have to take a break for a year or so for it to have an effect on the final result.

This is a very significant question, since the outcome will in all likelihood also determine the stamina needed to continue encouraging the child to comply with the treatment. A answers offer a possibility of negotiating with the child in cases of reluctance to adhere to the treatment. B answers do not, while C answers may prepare for a more laissez-faire attitude towards interruptions of the treatment.

Group comparisons

In the following, the experimental and the control group will be compared as to their distribution over the different categories. Generally, it has been possible to order the categories of outcome for a question hierarchically, i. e. answers belonging to an A category reveal a deeper insight into the phenomenon in question than do B answers, etc. The level of insight is thus defined in terms of the degree of concordance with the meaning conveyed by the information provided by the health care personnel. In most cases, it has been comparatively easy to identify the "correct" answers, whereas the order between remaining categories has been determined through a process of negotiation between two educational psychologists and three ophtalmologists, based on their interpretations of the educational material, the questions and the answers to them. In some cases, the categories of understanding have, however, not been possible to order hierarchically. Since these cases do not permit any statements as to differences between the groups in terms of level of understanding, they have been omitted in the group comparisons

Table 1. Comparisons between the control and experimental group in terms of the different levels of understanding. (Numbers are given in per cent.

*U a = uncategorisable answers. 1 and 2 refer to the two interviews.)

Question	Category	E-group 1	E-group 2	C-group 1	C-group 2
1. The meaning of refractive errors	A	0	31	0	10
	B	0	16	0	3
	C	10	0	10	3
	D	53	21	31	22
	E	0	5	0	3
	U a*	37	27	59	59
2. The effects of strabismus on binocular vision and amblyopia	A	21	37	0	0
	B	21	5	10	6
	C	5	5	25	16
	D	0	0	6	13
	U a*	53	53	59	64
3. The conditions for the development of normal vision	A	4	21	7	15
	B	16	21	7	10
	C	37	21	22	13
	D	0	5	5	3
	U a*	43	32	59	59
4. The reasons for treatment with occlusion and with glasses	A	15	26	12	25
	B	0	0	8	9
	C	11	21	8	9
	D	21	5	13	3
	E	0	5	13	6
	U a*	53	43	46	38
5. The reasons for an early onset of the treatment	A	5	11	6	13
	B	63	63	38	41
	C	5	5	0	0
	U a*	27	21	56	46
6. The reasons for surgical treatment of strabismus	A1	1	5	0	6
	A2	4	5	12	13
	U a*	95	90	88	82

continued

Question	Category	E-group		C-group	
		1	2	1	2
7. Does monocular vision improve after surgery?	A	0	5	0	13
	B	10	15	12	6
	U a*	90	80	88	81
8. Is the patient able to avoid wearing glasses after surgery?	A	0	11	4	6
	B	10	5	14	0
	C	0	0	0	6
	U a*	90	84	82	88
9. The determinant of the duration of the treatment	A	15	27	10	9
	B	53	21	22	31
	C	0	11	9	6
	U a*	32	41	59	54
10. The effects of an onset of treatment around the age three or at the age of fifteen	A	25	42	12	21
	B	48	37	54	60
	U a*	27	21	34	29
11. Any negative short-term effects?	A	40	42	16	22
	B	49	37	46	44
	U a*	11	21	38	34
12. Which eye is covered in occlusion?	A	100	100	100	100
13. The effects of strabismus on vision	A	15	22	9	21
	B	43	47	17	9
	C	21	11	10	9
	U a*	21	20	64	61
14. Consequences of interrupting treatment	A	10	22	10	21
	B	36	47	27	17
	C	22	11	29	19
	U a*	32	20	34	43
15. Consequences of interruptions of the treatment for a month	A	10	21	17	25
	B	20	32	22	19
	C	49	48	32	32
	U a*	21	0	29	24

If the outcome of the post test is studied on the level of individual questions, there are, of course, differences as regards importance, e.g. a crucial question concerns *the meaning of refractive defects*. Forty-seven per cent of the subjects in the experimental group are found in categories A and B, which indicates some understanding of the phenomenon, whereas the corresponding proportion in the control group is thirteen per cent. An even more convincing difference is found when comparing the distribution of the answers to the question about *the effects of strabismus on binocular vision*, where thirty-seven per cent of the experimental group subjects are found in the A category. None of the control-group parents is represented in this category. Furthermore, the distribution of answers to the question about *the conditions for the development of normal vision*, reveals a substantially higher level of understanding amongst experimental group subjects. There are three times as many experimental group subjects in the category described as "*the duration of the treatment* depends on the development, i. e. the development of vision", compared with the control group. Twice as many in the experimental group state that somatic reasons facilitate the treatment of a younger child compared with a teenager, and a difference of equal magnitude is found between the groups as regards the fact that negative *short -term effects* of vision impairment are of a somatic nature. Regarding the question about *what strabismus means to vision*, a majority of the experimental subjects are found in the A or B category, while only a third of the control-group subjects have been categorised as belonging to any of these. Similar differences apply to their conceptions about the effects of *interruptions of the treatment*. In four cases, *the reasons for an early onset of the treatment, the stated reasons for surgical treatment of strabismus, improvement of monocular vision after surgery* and *consequences of interruptions of treatment for a month*, there are a difference in the opposite direction.

The relatively high frequency of uncategorisable answers may seem to be a complication of the results. Experience shows, however, that this is a common outcome, particularly in cases where natural science concepts have been the subject of investigation(Johansson et al, 1985). In most cases, the uncategorisable answers are signs of ignorance. In other cases, they are simple restatements of the question or taken-for-granted like, "the vision is there and there is nothing more to say about it". Several subjects, most of them belonging to the control group, gave ignorant answers to many questions. There is also a high degree of stability in that several of the subjects who gave uncategorisable answers at the first interview did so even on the second occasion.

Chapter 8.

A qualitative analysis of health beliefs

In most studies where the Health Belief Model has been used, the variables are measured by a scale and/or structured questions with fixed alternatives. In the present study, as mentioned earlier, a questionnaire consisting of 43 items was used. These items covered three domains; Health Motivation, Value of Reducing the Threat and Probability of Reducing the Threat. Health Motivation consisted of four subheadings, namely *the feeling of physical threat, the feeling of having control over the state of health, having medical motivation and being anxious about the child's general state of health*. The domain was covered by 16 items.

Value of Reducing the Threat with three subheadings, *the child's vulnerability, the degree of physical injury in the case of the child* and *interference with the social roles of the parents* was covered by 12 items.

Probability of Reducing the Threat with the three subheadings, *confidence in diagnosis, experience of the effect of the treatment* and *belief in modern medical science* was covered by 15 items.

A weakness when using a questionnaire with fixed response alternatives is that the subjects do not get an opportunity to express themselves. This will lead to a loss in depth when coming to the interpretation of the responses.

To tackle this problem some of the variables in the Health Belief Model scale were also measured by means of open-ended questions in the introductory and in the second interview. This condition gave an opportunity to make an "qualitative factor analysis" of the data. The analysis was carried through by the author and another educational psychologist.

The scale items and interview items were sorted and judged together with the answering responses. The analysis gave the result that when regarding the whole body of data, irrespective of measuring tools and which variable in the Health Belief Model it intended to test, the following "factors" could be distinguished.

A. Health and illness
B. Health motivation and contacts with hospital
C. Threats to the health of the child

A. Health and illness
B. Health motivation and contacts with hospital
C. Threats to the health of the child
D. Information
E1. The family's responsibility for the treatment
E2. Expectations on the treatment
E3. Deviations from the treatment routines
F. Social effects
G. The value of controls at the ophtalmological clinic
H. Empathy by the nursing staff and nursery school personnel

The outcome of the control and experimental group is described under the heading "pre-test". Only changes from pre-test to post-test are described under the heading "post-test".

A. Health and illness

This area is about to what extent does a person holds himself responsible for his own health?(Item 24,30,32,55 in the Health Belief Model scale).

Pre-test: In the pre-test more than fifty per cent of the parents studied, both in the experimental group and the control group expressed a deterministic opinion when it comes to health. Diseases are something you get " if you are going to get them".

In spite of this, nearly about fifty per cent of the parents (regardless of whether they belong to the experimental or control group) think that ill-health is connected with way of life; "how you take care of yourself".

There is no difference between the parents in the control group and those in the experimental group in this respect.

Post-test: In the post-test there is a difference between the experimental group and the control group. Still, more than fifty per cent in the control group have a deterministic view of illness, while the proportion of the parents in the experimental group with this opinion had decreased to twenty-five per cent.

It is interesting to note the discrepancy shown above between the deterministic view of health and the fact that many still think that way of life is important to the individual's health status. When asked about medical motivation, the majority also said that they were definitely motivated to carry out the treatment after they had attended the medical care. This could possibly be interpreted to mean that, apart from the origin of diseases, they see them as curable, or that they themselves make a differentiation between " self-inflicted disease" and diseases thought to be beyond the individual's own control. This possible differentiation is, however, not evident from the answers as the response alternatives are formulated à priori.

The change in the experimental group between pre-test and post-test could possibly be explained by the fact that they understood, as a result of the education they had been given, the connection, as regards amblyopia, between treatment carried out and improved acuity of vision.

B. Health motivation and contacts with hospitals.

This section is based partly on items from the Health Belief Model scale (item 5,21,23,26, 28, 29, 56, 59) and partly on questions in the introductory and the second interview (question 10, 12).

Here, the area is about how interested the parents are in controlling their own health. What are their opinions of treatment in connection with hospital visits, and of the intelligibility of the prescriptions provided?

Pre-test: Only one of the responding parents belonging to the experimental group is uncertain about whom to contact if he/she or someone else in the family falls ill. About sixty-six percent both in the experimental and the control group, report that they occasionally have a health check-up even if they are not directly ill. In many studies, it has been found that possession of a thermometer and checking one's own temperature are related to compliance (Becker, et al 1972, a,b). About fifty per cent of the parents in the control group said that they check their own temperature often, whereas the other fifty per cent do so seldom or never. Twenty-five per cent of the parents in the experimental group check their own temperature often. About sixty-six per cent of the parents do not think that it is hard to understand prescriptions and advice, and the same proportion say that they usually comply with prescriptions given them. This applies to both the experimental and the control group.

Almost without exception, the parents in both the experimental and the control group feel that the nursing staff wants to help when they visit the hospital. Twenty-five per cent of those questioned do, however, think that the nursing staff may often be negative and almost half feel that the doctor sometimes thinks that they ask for help for a mere trifle. This does not mean that they " feel silly" if they have to attend subsequent check-ups for the same disease. About sixty-six per cent of the parents in the experimental group and almost equally many for the control group, think that the nursing staff sympathise with the fact that you can feel lonely and anxious, even if they tell you that the child is fairly well. (Compare with area G).

Post-test: There are no large differences between the pre-test and the post-test. The proportion of parents who think that the nursing staff is often negative dropped to about seventeen per cent in the experimental group and about thirteen per cent in the control group.

Of course, the attitude of an individual may be influenced by the way one feels treated by the nursing staff. In this case, most of the informants say that the nursing staff want to help them, but in spite of the fact that the twenty-five per cent in the pre-test felt that the nursing staff can be negative, and nearly fifty per cent of those questioned are of the opinion that the doctor thought that they came unnecessarily. It is not unreasonable that the attitudes of the nursing staff reflect whether they see the patient's visit as justified or not. The majority of the parents say that they want to have a health check-up at some time or another, even when they are not directly ill.

C. Threats to the health of the child

This area is about physical threats against the health of the child (item 1, 17 in the Health Belief Model scale.

It has been found that parents who felt that the child often got ill and who thought that illness was an important threat to the child, were more likely to administer medication. (Becker et al, 1972,a).

According to the Health Belief Model scale about sixty-six per cent do not think that the child is more susceptible to infections than other children. This applies to both the experimental and the control group.

Most parents do not regard checking to see that their child is getting sufficient nutrition and vitamins as a problem. Giving vitamins is also positively related to compliance (Becker, et al, 1972,a)

Pre-test: According to the Health Belief Model scale, eighty per cent of the parents do not think that their children are more susceptible to infections than other children – irrespective of whether they belong to the experimental group or the control group.

Post-test: During the post-test there is a small difference in the parents' perception of their child's susceptibility to the illness in as much as that in both the experimental group and the control group the children are regarded as being more susceptible than during the pre-test. The difference is greater in the experimental group where forty per cent of the parents regard their child as being more susceptible to infection than other children. The corresponding figure in the control group is just over twenty per cent.

The results do not indicate that the parents feel that the child is exposed to physical threats to a notably high degree when it comes to "ordinary complaints". There is a small change in the post-test, possibly due to the fact that some parents changed the focus of their attention after the pre-test. However, the results do not indicate any greater tendency to over-protect the child because they regard it as being more susceptible then other children. Nevertheless, they take strabismus seriously and think that it constitutes an obvious physical threat. (Compare with area E2, E3).

D. Information

Responsibility for information, channels of information and the feeling of having knowledge about the illness and its treatment are discussed under this heading.

Questions about information were asked in the Health Belief Model scale (item 22, 33, 50, 53,62) and in the introductory and the second interview (question 4, 5, 6, 7, 8, 9).

Pre-test: More than fifty per cent of the parents think that they have accomplished what they desired during their visits to the doctor. They report that they themselves see to it that they get what they want when they visit the doctor. About sixty-six per cent say that they acquired knowledge about strabismus above all at the ophtalmological clinic. More than fifty per cent of those questioned say that they got their knowledge from friends and acquaintances. This applies to both the experimental and the control group. About sixty-six per cent of the parents in the control group and eighty per cent in the experimental group think that they know about the consequences of not completing the treatment.

Most of the parents are satisfied with the results from their visit to the doctor, they think that they have got what they had expected. They also feel responsible for making sure that they get the information they need. It is also interesting to note that about seventy-five per cent think they got specific information about strabismus from the ophtalmological clinic while about fifty per cent say that "friends and acquaintances" have been an important, and sometimes the most important source of information. These figures are about the same for both the experimental and the control group.

It is interesting to note that a large proportion of the parents think that they got most information from ophtalmological clinic as well as from acquaintances. The fact that so many parents say that they know the consequences of non-compliance is perhaps logical when considering their statement that they themselves take responsibility for getting the information needed.

Post-test: At the post-test, the parents in the experimental group are more satisfied than the parents in the control group are. Almost 95% in the experimental group believe that they got what they wanted at the visit at the physician, the corresponding figure for the control group is about 60 %.

Almost all the parents in both groups say that they had got the most important information about strabismus at the ophtalmological clinic. Probably the difference between the groups depends on the special treatment of the experimental group. The experimental group was also given a specific question about its attitude to the booklet which revealed that generally speaking, the participants were satisfied with it.

E1. The family's' responsibility for the treatment

Here the area of the family's responsibility for the treatment is discussed (Item 39, 43, 45, 51 in the Health Belief Model scale).

Pre-test: In almost all cases, the whole family is involved in making the child comply with the prescriptions. Only in twenty-five per cent of the families does the mother think that she has the main responsibility for the prescriptions being adhered to. About fifty per cent of the parents think that in comparison with the work of the nursing staff, the contributions of the mother and the father are equally important. This is the same for both the experimental and the control group.

Post-test: The only difference between the groups is that somewhat fewer mothers in the experimental group believe that they have the main responsibility for the treatment. (twenty-five per cent against twenty per cent earlier).

E2. Expectations on the treatment"

In the introductory and the second interview (question 1 2, 3) and in the Health Belief Model(item 25, 34, 37, 44, 52) questions were asked about the expectations of the parents as to how the treatment would be experienced, on one hand for themselves and on the other, for the child.

Pre-test: Just under twenty-five per cent of the parents in the experimental group and about thirty-three per cent in the control group thought that the treatment would not present much of a problem as far as they were concerned. Among the reasons referred to was that they themselves wore spectacles and did not think that there was anything unusual about it, or that the child was so very motivated. About sixty-six per cent in both groups believed that the treatment would cause some discomfort, they thought that it would take time for the child to get accustomed to spectacles and an eye-patch. Furthermore, they thought that the visit to the ophtalmological clinic might cause difficulties because it would mean taking time off work. None of the parents, however, thought that the treatment would be almost impossible to carry out.

Questioned about what they thought about how the child itself would experience the treatment, almost 80 per cent in the experimental group and 76 per cent in the control group responded that it might be somewhat difficult. Above all, they thought that the spectacles would be an obstacle in various activities, wearing an eye-patch could lead to visual difficulties and irritation, because the eye-patch covers the "best" eye. Moreover, they felt that the repeated visits to the ophtalmological clinic might prove to be a strain on the child.

Only about 10 per cent of the parents in both groups believed that the child would not experience any problems in connection with the treatment. About eighty per cent of the parents thought that the normal treatment gave the best chance of a positive result. Only three parents, in the control group, did not believe that the prescriptions provided could be fully trusted. You have to design your own regimen from experience. About eighty per cent of the parents also thought that they had observed that the child saw better when adhering to the prescriptions. About 50 per cent of the parents gave opinions ranging from " a little difficult" to "it does not work at all". The difficulties named were based on their own experience of treatment as well as what they observed in their children. What they emphasised were somatic consequences such as skin irritation, forgetfulness, i.e. you forget to carry out the treatment daily, indications of physical discomfort in the child such forgetting its spectacles, being teased because of the eye-patch and so on. In many cases, they also mentioned practical consequences of treatment, e.g. the spectacles fall off when the child is playing. They also said how difficult it was to be consistent in the treatment, partly due to the reasons given above, that is to say, that the child refused. Ten per cent of the parents thought that the intensity of the treatment prescribed was exaggerated, others referred to the doctor saying that the child has good visual acuity in one eye, and then they drew the conclusion that there was no need to exaggerate the importance of the treatment.

It should be observed that eighty per cent of the parents had a quite different opinion. They thought that the treatment had been fairly unproblematic and that they carried out the treatment very consistently. These parents said they were motivated because the doctor had made them understand the importance of carrying out the treatment. Some parents thought that it had been easy to be consistent as the child had been easy to motivate.

Post-test: The questionnaire showed that about seventy-five per cent of all parents thought that the treatment involved a lot of inconvenience for themselves. Above all, they had to ensure that the child really wore its spectacles/patch and in many cases this meant that they had to nag the child a lot.

About fifty per cent of the parents in both control and experimental group thought that the child had felt some discomfort in connection with the treatment. A prerequisite of making a family take responsibility for carrying out the treatment is that they really believe that it will result in progress. The reason why the majority regarded the prescribed treatment as optimal might have been that most of them noticed a positive effect of a compliant behaviour, i.e. visual acuity improved. If parents believe in the treatment, see the effects of it and think that it is adequate, the probability of a reduction of the threat increases.

E3. *Deviations from the treatment routines*

This area concerns the importance of compliance and the effects of non- compliance as well as the attitudes about changes in treatment (item 12, 13, 19, 27, 36, 48, 49 in the Health Belief Model scale).

Pre-test: All the parents say that they agree on the importance of getting the child to understand that it is imperative to behave carefully during the whole period of treatment. Almost none of the parents hesitates to nag the child if necessary. About sixty-six per cent of the subjects say that they do not make allowances because the child " is small and needs to play". Opinions about the consequences of occasional non-compliance, e.g. neglecting the prescriptions once or twice a week vary considerably. About sixty-six per cent of the parents do not think that the child should be allowed not to wear and eye-patch/spectacles when going to a party, even if the child should want to. In the questionnaire, there are questions about how the parents feel about the need to be consistent in their treatment of the child.

Five of the parents think that it is hard to be consistent because the child is disobedient. Sometimes it has been so difficult that at the ophtalmological clinic they have considered giving the child eye drops (comment: to paralyse accommodation and blur vision) instead of an eye-patch and spectacles Parents may also find it difficult to carry out the treatment consistently because they are not sufficiently motivated themselves. In ten cases, according to the parents, they believe that the doctor has exaggerated the intensity of the treatment. These parents thus deliberately choose to be inconsequent. In six cases forgetfulness is the stated reason. There are, however, a number of parents, fifteen, who say that they are aware of what will happen if they do not comply with the prescriptions, and therefore do not dare to not comply.

According to the Health Belief Model scale, there are very few parents who say that they increase the degree of compliance on the days before visiting the ophtalmological clinic. Nor are they afraid of telling the doctor/orthoptist if they have deviated from the prescription.

The belief that the doctor takes the correct measures when changing the treatment and the instructions varies considerably. About thirty-three per cent of the parents in the control group think that the doctor acts correctly, about thirty-three per cent thinks that he does not act correctly and the rest express uncertainty. In the experimental group, over eighty per cent of the parents believe that the doctor acts correctly and only about twenty per cent are uncertain.

Post-test: The greatest difference between pre-test and post-test as regards "Deviations from the treatment routines" concerns confidence in the physician being right if he wants to make changes in the treatment. Only fifteen per cent of the parents in the control group believe that the doctor acts wrongly in this question. In the experimental group, this attitude was expressed already in the pre-test, and did not change in the post-test.

It is obvious that the parents stress the importance of compliance, at the same time as they claim that they accept occasional non-compliance. Of interest is what "carefully attend" means to them. According to the parents, occasional non-compliance, such as neglecting the prescription once or twice a week is tolerable.

In the pre-test, the parents also say that they may sometimes feel uncertain as to whether the doctor really acts correctly when changing the prescription, but the majority (compare with area E2) said earlier that the treatment is the best condition for normal improvement of visual acuity. The post-test shows that there has been a change and that they have more confidence in the doctor doing right thing.

F. Social effects

This area concerns the social consequences for the family and the child (item 2, 4, 8, 14, 15 , 40, 41, 42, 46, 57 in the Health Belief Model scale and questions 15 and 16 in the introductory and the second interview).

Pre-test: Almost all parents state that they also discuss matters concerning the family among themselves. Ninety per cent categorically deny that the treatment has any social consequences. For example, they do not think that the illness has had any influence on their family or contacts outside the home. They do not think that they will have less spare time because of the treatment nor that the family will face more problems than other families, because of the child's illness. This applies to both the experimental and the control group. In general, they do not think that the child is affected to any great extent, e. g. worse relations with comrades. When it comes to the choice of profession facing the child in the future, they generally do not believe that it will be limited because of long-term effects of strabismus. There is, however, a small difference between the experimental group and the control group; the experimental group parents are a little more uncertain about their child's freedom to choose a profession

Post-test: The difference between the experimental and the control group concerning future choice of profession is the same in the post test.

The second interview showed that the experimental group to greater extent , (forty per cent) than the control group(twenty per cent) believes that the disease might affect what sports the child can participate in. They understand that, for example, some ball games can pose a problem as they require binocular vision. The second interview also showed that some children had been teased because of the spectacles and not allowed to partake in playing.

G. The value of check-ups at the ophtalmological clinic

Here the area of the value of check-ups at the ophtalmological clinic is discussed (item 18, 54 in the Health Belief Model scale).

Pre-test: Almost all the parents are very much in favour of regular check-ups/return visits and think that they give a sense of security. On the other hand, about thirty-three per cent of the control group and twenty-five per cent of the experimental group think that the nursing staff focus too narrowly on the test results during the return visits, and that they do not show the same interest in how the treatment may affect the child's life in other respects.

Post-test: A difference can be observed in the post-test. Nearly eighty per cent of the parents in the experimental group say that the nursing staff show an interest in the child as a person and not only as " a disease". In the control group, about thirty-three per cent of the parents still feel that the nursing staff are most interested in the test results.

Nearly thirty percent of the parents in the pre-test think that the nursing staff are less interested in other consequences of the treatment which are not of a purely medical nature. It is interesting to note that the parents practically deny the presence of "social effects of the treatment"(compare with area F). The question is whether it is other consequences that this nearly thirty percent of the parents are thinking about, whether the remaining thirty per cent are thinking about other consequences or, finally, whether the interpretation could be that they want more empathy from the nursing staff. The difference between the experimental group and the control group in the post-test could possibly be explained by spin-off effects of the experimental condition. Perhaps the nursing staff take more time with the parents, perhaps they talk more about other matters concerning the disease and not only test results.

H. Empathy shown by the nursing staff and the nursery school personnel

This section is based partly on items from the Health Belief Model scale (item 7, 11, 16) and partly on questions from the introductory and the second interview (question 11, 13, 14)and discusses the empathy shown by the nursing staff and the nursery school personnel.

Pre-test: A little more than fifty per cent of the parents generally think that they have been met with understanding on their visits to the hospital. This means, however, that almost half of them do not feel that they have been received seriously during their visits. This is illustrated by the fact that twenty-five per cent of the parents think that even the department for the promotion of children's health has been too passive in reporting suspect strabismus cases to the ophtalmological clinic. In the case of the ophtalmological clinics, about sixty-six per cent are of the opinion that the nursing staff think that the parents manage the treatment well. When it comes to the nursery school and its personnel, eighty per cent of the parents think that they show empathy with the child's visual handicap and its treatment.

Post-test: The difference between pre-test and the post-test is that in the post-test, almost all parents said that they had been met with understanding during their visits at the ophtalmological clinic. This applies to both the experimental and the control group.

The fact that the nursery school personnel show understanding ought to make it easier to carry out the treatment, as many children usually spend a large part of the day, and thus also the treatment time, there. It ought therefore be important to the parents that the nursery school personnel have a positive attitude.

Chapter 9

The development of visual acuity

The amblyopia treatment was based on changes in visual acuity. The analysis of visual acuity improvement includes the changes with time in absolute values and in percent of the previous value for each individual during a period of 0 - 18 months after confirmed diagnosis. Values for the nonamblyopic eye are used as a measure of normal development. Visual acuity was measured with methods adequate for the age and values transformed to Snellen equivalents (see chapter 6).

At the eighteen-month follow up it appeared that not all children in each group had been tested with respect to visual acuity. Data on visual acuity for 27 children in the experimental group and 29 children in the control group were missing. The dropout was beyond the author's control. One of many conceivable explanations for the dropout is that, for some reason, the personnel at the clinic in question had not noticed whether a child was assigned to the study or not. Anyhow, as the dropout is of the same size in both groups, it can only be assumed that the dropout is random. Consequently there are measures of visual acuity for 32 children in the experimental group and 31 children in the control group. In table 3 the measures of percent change in visual acuity in order of rank for the individuals of the experimental group are shown.

The percent is presented in whole number.

Table 3. Percent change in visual acuity in the experimental group N=32

Individual	Percent change	Individual	Percent change	Individual	Percent change	Individual	Percent change
1	0	9	50	17	100	25	150
2	20	10	54	18	100	26	200
3	25	11	54	19	100	27	200
4	25	12	54	20	125	28	200
5	25	13	54	21	125	29	300
6	33	14	67	22	133	30	650
7	39	15	75	23	150	31	700
8	43	16	100	24	150	32	900

As the data in the distribution showed in table 3 is on ratio scale level, the mean can be used as a measure of central tendency and standard deviation as a measure of variability. The mean of visual acuity for the experimental group is calculated at 156.2 and the standard deviation at 207.8. But going further in the analyses of the distribution, the measures of kurtosis (Ku) and skewness (Sk) give the result; Ku=5.15 and Sk=2.45. According to Sprinthall (1987) any value of skewness greater than + -1.00 indicates marked skewness. As our Sk is 2.45, it indicates that the distribution is unbalanced (skewed), with few extreme scores in any direction. Kurtosis refers to the degree of the curvatore of an unimodal frequency distribution; it is about the peakedness or flatness of the curve. Further according to Sprinthall (ibid), when it comes to kurtosis, 3.00 defines a mesokurtosis (the normal curve). Our Ku- value of + 5.15 indicates the distribution is a leptocurtic curve. This means a unimodal frequency distribution in which the curve is relatively peaked, and most of the scores occurring in the middle of the distribution, and with very few scores in the tails.

The histogram in figure 3 illustrates the above reasoning.

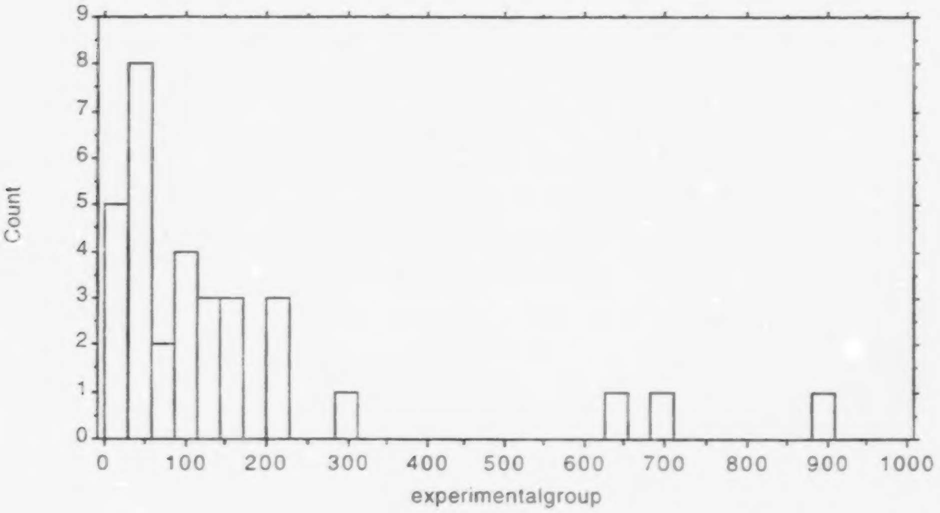


Figure 3. Percent change of visual acuity for the experimental group. N=32

From figure 3 it can be easily seen that the distribution is unimodal, leptocurtic and positively skewed. According to Guilford(1956) the median gives the best index of central tendency when working with skewed distributions and the semi- interquartile range (Q) the best index of variability. Accordingly the median was computed, and the value arrived at was 99.8 and Q was estimated at 51.75.

Table 4. Percent change in visual acuity for the control group. N= 31

Individual	Percent change	Individual	Percent change	Individual	Percent change	Individual	Percent change
1	- 20	9	80	17	150	25	300
2	25	10	80	18	167	26	300
3	39	11	80	19	167	27	375
4	46	12	100	20	167	28	400
5	54	13	133	21	200	29	500
6	54	14	133	22	200	30	567
7	75	15	150	23	200	31	700
8	75	16	150	24	200	32	

As in the experimental group the data is on ratio scale level and the mean is calculated at 188.6 and the standards deviation at 203.45. Estimating the skewness and kurtosis gives the result Sk= 1.49 and Ku= 1.73. This indicates a distribution similar to the the experimental group. The histogram of figure 4 confirms this reasoning.

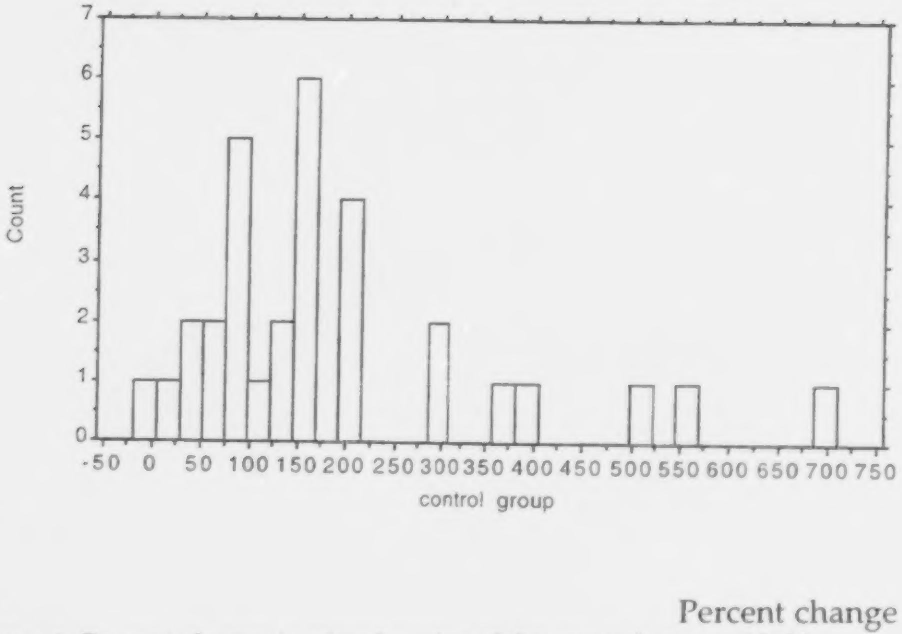


Figure 4. Percent change in visual acuity of the control group. N=31

As figure 4 shows, the distribution for the control group is, like the distribution for the experimental group, positively skewed. The best measure of central tendency is therefore the median and the best variability measure is Q. For the control group the median was calculated at 150.1 and the Q at 61.9.

The distributions of the experimental group and the control group are very similar with both being positively skewed. The distributions show that most children have increased their visual acuity during the treatment period by 100 to 150 per cent. The value of the medians indicates that the individuals in the control group have increased their visual acuity a bit more compared with the individuals in the experimental group.

Chapter 10

A quantitative analysis of health beliefs, knowledge and visual acuity. A comparison between the groups.

The quantitative analysis presented in this chapter consists of three parts. The first part analyses the attitude variable, that is the Health Belief Model scale. The second part concerns the knowledge variable. In chapter 7 the results of the phenomenographic interview and a qualitative analysis were presented. Here a quantitative analysis to determine whether the differences between the experimental group and the control group are significant is applied. In the third part all the relations between variables are tested.

The attitude variable - the Health Belief Model

The attitude scale consists of three sub-scales: General Health Motivation, Value of Reducing the Threat and Probability of Reducing the Threat. The subscale General Health Motivation measures the direction and the strength of general health motivation, whereas the other two sub-scales measures the attitudes towards the specific illness. The results of the measurement are presented in table 5.

Table 5. Mean scores from the pre-test and the post-test of the Health Belief Model scale.

	Control group		Experimental group	
	Pre-test	Post-test	Pre-test	Post-test
General Health Motivation	3.6	3.5	3.5	3.6
Value of Reducing the Threat	2.0	2.1	2.2	2.5
Probability of Reducing the Threat	4.2	4.2	4.3	4.5

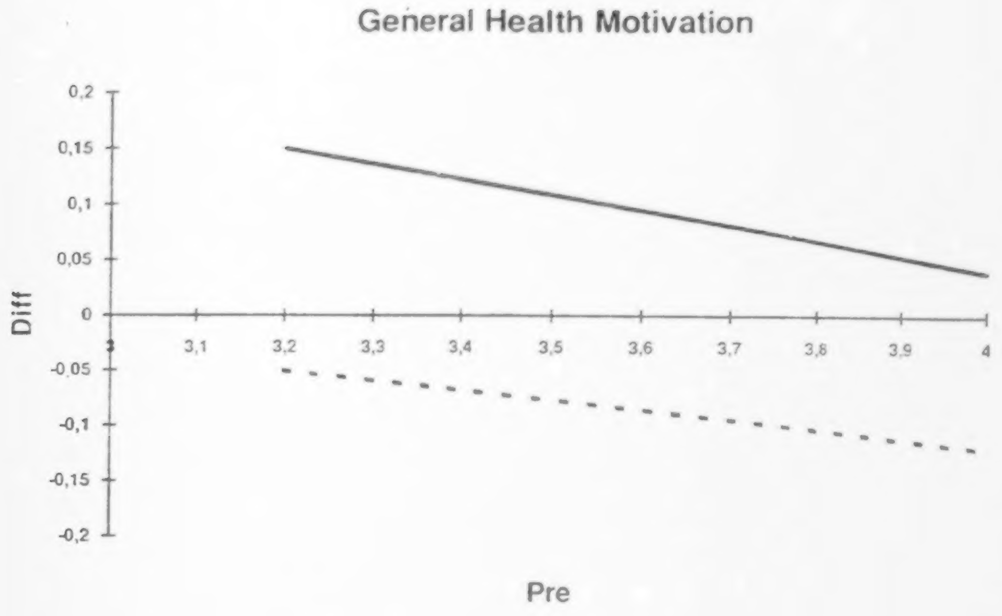
A score of 2.5 or less indicates theoretically, an attitude, which does not support a compliant behaviour. A score of 3.0 or more indicates, still theoretically, an attitude, which support compliance.

As can be seen in table 5, there are initial differences between the experimental group and the control group. Accordingly the two groups have been compared with regard to the three differences and with the influence of the prevalue eliminated. Finally, the reason for elimination of the influence of the pre-values is that there was a significant difference as regards Value of Reducing the Threat ($p= 0.0015$) and tendencies to significant differences as regards General Health Motivation ($p= 0.1006$) and Probability of Reducing the Threat ($p= 0.1065$). Mantel's (1963) test has been applied. The result of the test was, that the differences were significant in all three sub-scales ($p< 0.001$, two-sided). To illustrate the differences between the experimental and the control group, linear analysis of regression was applied. The following equation has been used: $Y=a + bX$. The regression coefficient (b) and the intercepts (a) are shown in table 6.

Table 6. Regression coefficients and intercepts for sub-scales in the Health Belief Model scale

		Experimental group	Control group
General Health	a	0.625	0.241
Motivation	b	- 0.147	- 0.090
Value of Reducing	a	1.054	0.311
the Threat	b	- 0.355	- 0.122
Probability of Redu-	a	1.777	0.806
cing the Threat	b	-0.369	- 0.195

The difference between the groups has been eliminated as a function of the prevalue within each of the two groups. The outcome can be seen in figure 5 - 7.

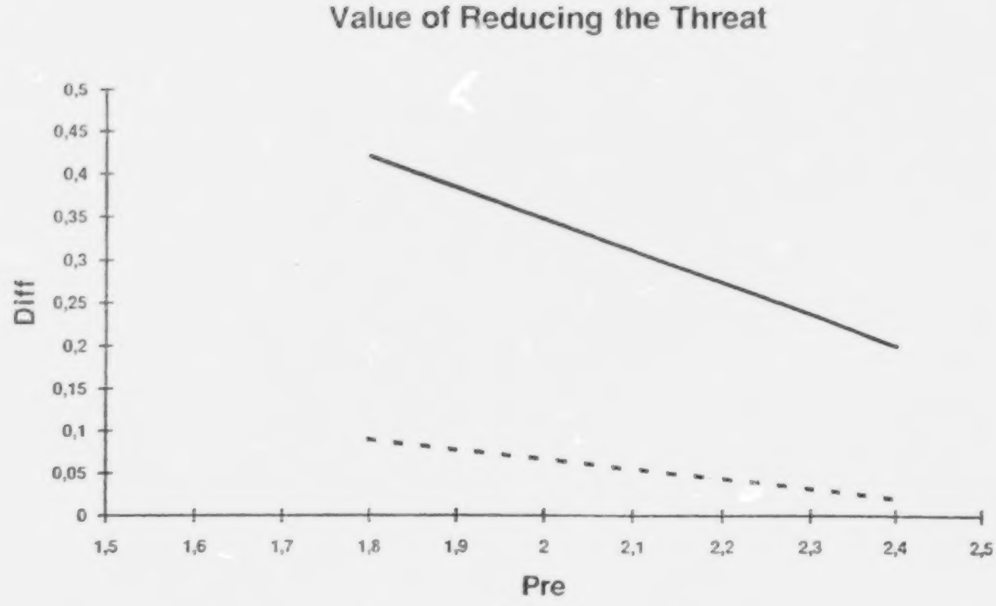


____ experimental group

- - - - - control group

Figure 5. Differences between experimental group and control group (pre- and post-test) regarding General Health Motivation

From figure 5 it can be seen that subjects in the experimental group with low values in the pre-test have increased more than those with high values in the pre-test. In the control group the subjects with low values on the pre-test have decreased less than the subjects with high values in the pre-test.



_____ experimental group

- - - - - - control group

Figure 6. Differences between experimental group and control group (pre- and post-test) regarding Value of Reducing the Threat.

As can be seen in table 6, there is the same trend in both the experimental group and the control group; subjects with low values in the pre-test increase more in the post-test compared with subjects with high values in the pre-test.

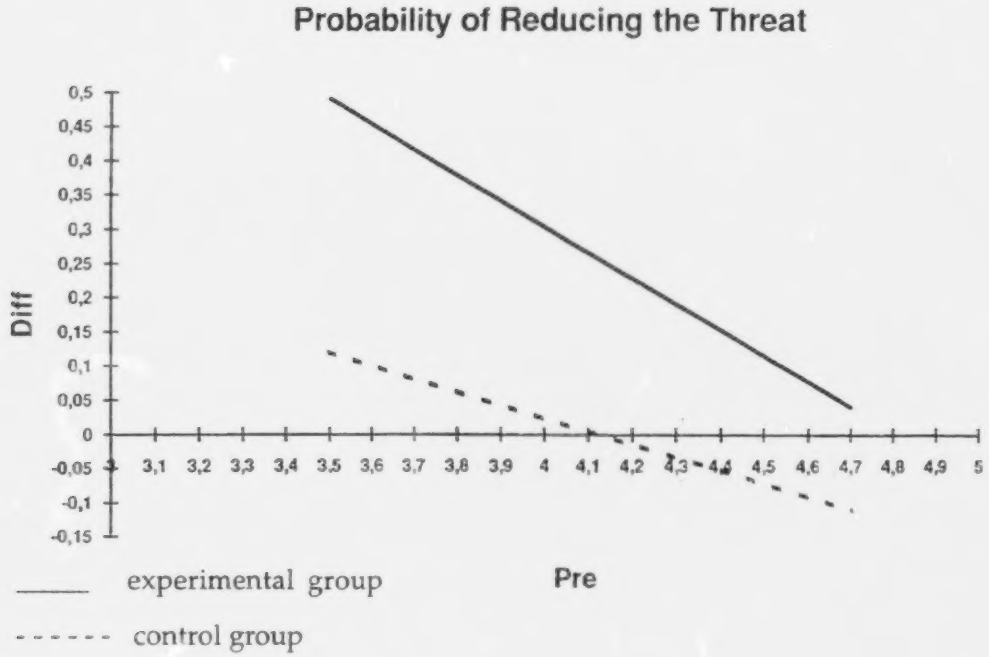


Figure 7.Differences between experimental group and control group (pre- and post-test) regarding Probability of Reducing the Threat

From figure 7 it can be seen that the trend for the experimental group is the same as before: high score in the pre-test results in less change in the post-test. But in figure 7 a new trend for the control group can be seen. Subjects with low values in the pre-test increase in the post-test, but subjects with high value in the pre-test decrease in the post-test.

Knowledge

As mentioned before the knowledge of amblyopia and its treatment in the experimental group and control group was qualitatively analysed in chapter 7. In table 6 in chapter 7 a cursory examination shows that there is a difference in knowledge between the two groups.

To determine whether the differences in knowledge between the experimental and the control group were statistically significant, Fisher's permutation test (e.g. Bradley, 1968) was applied. This test can somewhat simplified be described as a non-parametric counterpart of the conventional t-test. First, the number of predecessors for each subject has to be determined. This means the number of subjects who are superior to a certain subject with regard to a certain category they have been assigned to in various questions. If a person is placed higher up in the hierarchy of conceptions in a greater number of questions than he has been placed equal or lower, than the subject in question is a predecessor to the subject with whom he is compared. Thereafter Fisher's permutation test was applied and the calculation formula Edgeworth's extension was used (see Bradley,1968). Using this test a p-value was obtained. The p-value is the likelihood that the superiority - or inferiority- of one group is random. In this case the p-value is 0.00024 (two-sided). Thus there is a significant difference between the groups, meaning that the experimental group has more profound knowledge compared with the control group.

Relation between variables

The percent change in visual acuity after 18 months from the start of the treatment, was used. As measure of compliance at that time visual data for 32 patients belonging to the experimental group and 31 patients belonging to the control group were available.

The following variables' relationship with change in visual acuity were tested:

a. Knowledge of the disease and its treatment

b. The sub-scales in the Health Belief Model (General Health. Motivation, Value of Reducing the Threat, Probability of Reducing the Threat)

c Belonging of group (Experimental or Control group)

The correlation between variables was tested by Pitman's test (see Bradley, 1968). This test is a non-parametric test not based on ranks. Two-tailed tests were used. Pearson's correlation coefficients and 95 % confidence intervals were calculated by use of the t - distribution.

The 95 % intervals of confidence are presented in table 7.

Table 7. P- values, two - tailed, for variables.

Variables	p - value, two - tailed
1. Percent change in visual acuity versus General Health Motivation	> 0.30 (0.9809)
2. Percent change in visual acuity versus Value of Reducing the Threat	> 0.30 (0.6339)
3. Percent change in visual acuity versus Probability of Reducing the Threat	0.0562
4. Group versus General Health Motivation	0>0.30 (0.4599)
5. Group versus Value of Reducing the Threat	0.0562
6. Group versus Probability of Reducing the Threat	> 0.30 (0.8097)
7. Group versus Percent change in visual acuity	> 0.30 (0.6052)
8. Knowledge versus General Health Motivation	> 0.30 (0.5065)
9. Knowledge versus Value of Reducing the Threat	> 0.30 (0.5739)
10. Knowledge versus Probability of Reducing the Threat	> 0.30 (0.6692)
11. Knowledge versus Percent change in visual acuity	< 0.001

In table 7 it can be seen that only the last tested relation between variables, (number 11), is significant. The significant value indicates that it is a relation between knowledge and compliance. Two relations between variables (number 3 and 5) are close to significance. Thus there is no significant relation where the variable Group (experimental or control) is included. It thus does not make sense to go further and compare the groups regarding possible differences between them when it comes to relations between two other variables (comparisons regarding functions of regression). In table 4 the estimated coefficients of correlation, with a confidence interval of 95 %, is presented.

From table 8 it can be seen that relation number 11, knowledge versus percent change in visual acuity is the only relationship that shows a substantial connection between each other.

Table 8. Coefficients of correlation

Number	R	95 % Confidence interval		
		Lower	Upper	
63	0.085	-0.166	0.326	Number of predecessors among those with values on visual acuity versus General Health Motivation
63	-0.073	-0.315	0.178	Number of predecessors among those with values on visual acuity versus Value of Reducing the Threat
63	-0.055	-0.299	0.195	Number of predecessors among those with values on visual acuity versus Probability of Reducing the Threat
63	-0.566	-0.714	-0.370	Number of predecessors among those with values on visual acuity versus Per cent change in visual acuity
63	0.008	-0.255	0.241	Per cent change versus General Healt Motivation
63	0.056	-0.195	0.299	Per cent change versus Value of Reducing the Threat
63	0.213	-0.037	0.438	Per cent change versus Probability of Reducing the Threat.

From table 8 it can be seen that relation number 11, knowledge versus per cent change in visual acuity is the only relationship that shows a substantial connection between each other.

Chapter 11

Discussion

As was stated in the introduction, the concept of compliance has a long history and has been of intense scientific interest in recent decades. As with scientific concepts in common, the concept of compliance gains its meaning depending on how it is operationalized. The question about criteria is of utmost importance. Hence, when from the outset of this study, the first issue was to find reliable and valid criteria of compliance. Change in visual acuity in connection with amblyopia is one such criterion. The disadvantages of the criteria are few. One example of a drawback might be the lack of co-operation of the child when measuring visual acuity. Change in visual acuity was however considered as more useful than to, for example,interview the child if he/she was seeing better. Many of the children in this study were also too young as well for answering the question as to estimate if there was an increase in visual acuity. Besides, such an estimate means a large amount of subjectivity.

Research on compliance has attempted to explain some of the variables that lead people to comply, or refuse to comply. The information variable is one that has attracted great interest. One conclusion which can be drawn from this field is that information is a necessary but insufficient factor for compliance. Few researchers have taken a step further in the information chain and considered the resulting knowledge in the patients and it's subsequent impact on compliance. Two studies where the knowledge aspect is studied are for instance the studies by Fallsberg (1991) and Kjellgren (1998).

The present study has its focus on the significance of knowledge as regards compliant behaviour.

In educational research on effects of instruction the measures applied have traditionally been quantitative, i.e. the subjects have been asked a series of questions, the answers to which have been judged as either correct or erroneous. The outcome is a sum of points indicating the knowledge level of the subjects. As has been pointed out previously, this is also the procedure generally applied in assessing effects of patient information. In this study the ambition has not merely been to asses the *amount of knowledge* observed, but also to describe the *kind of understanding* accomplished and whether this affects action; in this case, results in a compliant behaviour. The aim was further to study whether understanding affected attitudes towards the disease and the treatment, and whether these attitudes affected the result of the treatment.

The main results of the study is evident from figure 8

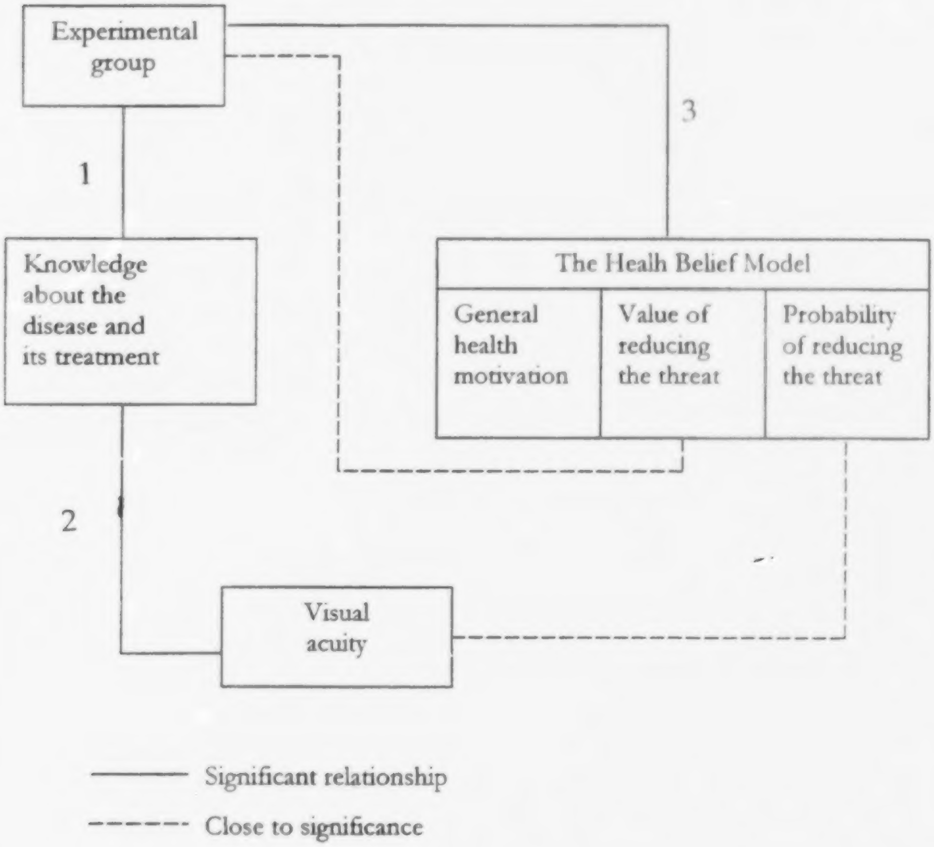

Experimental group
3
1
The Healh Belief Model
General health motivation
Value of reducing the threat
Probability of reducing the threat
Knowledge about the disease and its treatment
2
Visual acuity
Significant relationship
Close to significance

Figure 8. Main result of the study.

The results reveal a superior understanding among parents in the experimental group (relationship 1 in figure 8). If the hierarchies of conceptions, which are constructed from the answers of interview subjects, are studied, the members of the experimental group are more often found in the highest category. This means that they have a deeper insight into the field of amblyopia and its treatment (see Fisher´s test chapter 10). The experimental group had also changed attitudes towards disease and treatment in a direction that would favour compliance more than could be observed in the control group (relationship 3 in figure 8).

The most interesting finding in this study is the significant relationship between the parents' knowledge about amblyopia and its treatment and compliance as measured through the development of visual acuity. (relationship 2 in figure 8). Notice that the relationship applies to the whole group irrespective of belonging to experimental or control group. This means that parents with more profound knowledge have children who show a greater improvement of their visual acuity (because of the falling off of 56 patients there is a degree of uncertainty in the conclusions in this part of the study).

Apparently some knowledge of the disease and its treatment is more important when it comes to carrying out the treatment. As is shown in chapter 7, certain questions were posed concerning the consequences of interruption of treatment For example, if the parent thinks that interrupting the treatment will jeopardise the development of the child's vision, there are presumably incentives for convincing the child that the treatment is necessary despite the inconvenience it may cause. If, on the other hand, the parent thinks that an interruption will merely cause a stagnation in the development of the child's vision, it may be easier to agree to a temporary halt to the treatment.

The results in the pre-test of the Health Belief Model, showed that the parents in both the control and the experimental group had fairly high "general health motivation". This was measured by means of items constructed to measure 1. the feeling of physical threat, 2. the feeling of having control over one's state of health, 3. medical motivation, and 4. anxiety about the child's general state of health. A small change can be observed in the post-test – in the control group there is a slight decrease and in the experimental group a slight increase in general health motivation.

Value of reducing the threat, with subheadings 1. the child's vulnerability, 2. the degree of physical injury in the case of the child and 3. interference with the social roles of the parents, was very low in the pre-test for both groups. It increased somewhat in the post-test, but was still low. Perhaps the parents have a great faith in the treatment, or they do not realise what the disease can result in.

The probability of reducing the threat was measured by 1. confidence in the diagnosis, 2. experience of the effect of the treatment and 3. belief in modern medical science. This value was very high in both groups and increased even more in the post-test, especially in the experimental group.

However, the difference between the experimental and the control group was significant as shown in relationship 3 in figure 8, (see Mantels test in chapter 10).

As is evident from the results presented earlier, the supplementary, qualitative analysis of attitudes supports the traditional, quantitative analysis of the Health Belief Model.

The supplementary analysis of the attitudes also shows another interesting finding. About 50 per cent of the parents, irrespective of group, had a deterministic opinion regarding health and illness. In the post test, only 25 percent of the experimental group showed a deterministic attitude while 50 percent of the parents in the control group, still held this view. This means that 25 percent more in the experimental group thought it possible to influence if they should stay healthy or not. If one thinks that it is impossible to influence the occurrence of a sickness, then there is a risk, that this affects the treatment, consciously or unconsciously. If health care fails to get patients to understand, that they themselves could sometimes be responsible for the outcome of the treatment, then the possibility for the patient becoming involved in the treatment and asking for knowledge and information decreases.

The experimental group has better knowledge about the disease and its treatment. Accordingly we have reason to believe, that an increase of knowledge affects one´s confidence in the ability to affect the occurrence of the disease, and through active participation in the treatment affect the outcome.

Herzlich and Pierret (1987) carried through a large study about how people conceived their disease and conclude:

> Today, and for more than a century now, our attitudes toward illness decidedly favor action, struggle, and victory over biological misfortune. It is therefore all the more paradoxical that the notion of fate is still present in today´s sick (p.131).

In many studies of health beliefs it has been concluded that compliance with the regimen is better if the patient views his illness as a serious threat that can be effectively treated with minimal interference with his normal life (Alogna, 1980).

The parents do not, however, seem to conceive of amblyopia as a threat. Perhaps they believe in the possibility of treating and curing the disease. Perhaps the ophtalmologists and the orthoptists have not talked so much about future consequences of the disease and/ or they have succeeded in convincing the parents that the treatment really yields result if it is carried out. Consequently, the confidence in the treatment might have had a positive effect on motivation. It is also possible that, as the treatment proceeds, the parents have noticed an improvement of the child's visual acuity. This improvement in visual acuity might also be motivating. Factors that motivate people to begin and complete a treatment might change during the course of the treatment.

The parents demonstrated obvious interest in checking up their own health, something which a previous study (Maiman et al, 1977) showed to be a poor predictor of compliance with the treatment. It is probable that the opposite relation is not significant.

The parents in the control group seemed to feel that the child was exposed to physical threat slightly more than the parents in the experimental group. They also showed somewhat more concern about general health than the experimental group parents.

Most parents felt well-informed and did not think it hard to understand the prescriptions and advice they had been given about amblyopia and its treatment. The parents stated that they had understood the prescriptions. But it is first when a comparison can be made between the selfreported understanding and the knowledge as it appears in a knowledge interview that it is possible to evaluate this opinion. In this case, it is easy to check what the parents really know since it is one of the aims of this project. It is probably not unusual for a person with a superficial approach to learning to often overestimate his understanding.

It is not unusual that parents of disabled children allow the disability to have an effect to the whole individual. In this study, in general, one's own child is not perceived as marginalized, despite its disability. Probably spectacles are so well-established as a method of treatment that even if worn by small children, they do not attract much attention. The children often do not give the impression of being handicapped and most parents do not seem to be overprotective.

It is important to believe that the treatment will have an effect over extended periods. If the child makes progress, it will make it easier for the parents to carry out the treatment. The medical tests at the ophtalmological clinic are very important because they provide information about visual acuity, i.e. feed-back about the treatment. On the whole, it is important to ask what the parents believe about the effect of the treatment, even though the same illness does not necessarily lead to the same future for different patients.

The parents' confidence in the treatment is probably most important in the early phases of the treatment. As improvement in visual acuity become noticeable, other variables might become less important. The improvement of visual acuity becomes strongly motivating which may well overshadow all the other factors. In a prospective study of mothers' compliance with a diet regimen prescribed for their obese children, Maiman et al (1977) showed that weight loss itself could be an important motivational factor.

Of course, the opposite could happen. In this case if the visual acuity improves, the parents might not be motivated to continue with the treatment that could be needed for a while longer.

According to their own statements, the parents are very obedient They categorically deny any systematic deviation from the treatment, while occasional forgetfulness may be accepted.

It is interesting to note that in the pre-test, only one third of the parents in the control group, believe that the doctors are correct when changing the treatment, at the same time they express the opinion that the prescribed treatment is the best prerequisite of improving visual acuity.

One explanation of this might be that a change in the treatment could be interpreted as indicating that the doctor is uncertain about his prescription.

If the nursing personnel merely base their measures on the patient's ideas and expectations, their official health expert role is changed in a way that may appear to many patients as uncertainty on the part of the personnel, or even ignorance. Another explanation might be that different levels are referred to. Treatment with occlusion and spectacles is appropriate but marginal adjustments in e.g. the intensity of the treatment may be questioned.

According to the rating scale (HBM), no negative social consequences seem to have occurred as a result of the treatment. Comparing with the interview questions dealing with this subject , one finds that some children have been teased because of their spectacles, or have not been allowed to play with the other children. On the other hand, the duration of both the illness and its treatment does not seem to be such that it affects the family's social contacts. Another plausible version is that illness initially may have social consequences, but when routines have been established they are not experienced as restrictive.

It is evident that the parents have a positive attitude towards regular check-ups at the ophtalmological clinic and regard them as a safety measure. At the same time, they feel that the nursing staff focuses too narrowly on objective results, and do not always show empathy. The treatment in itself is not especially complicated, but it is important that it is carried out, and that it is checked to ensure that it results in a change. A possible explanation of the nursing staff prioritising objective results is that they do not themselves believe that the treatment will result in any negative social effects.

The supplementary analysis is not intended to be an alternative to the traditional analysis, its aim is to find another way of categorising the Health Belief Model items as well as to consider the questions about the parents attitudes in order to try to obtain a complete picture. The advantage of this is more detailed information, something that could be useful in medical care.

Patient education has often been used to try to change the perceptions which are thought to be negative to a compliant behaviour, and replace them with for example perceptions of severity and susceptibility, which medical care considers are thought to be more appropriate for compliance. (Ross & Guggenheim, 1983). This view has been criticised for ethical reasons among others by Richt (1992) who puts the question:

> Is it justifiable e.g. from an ethical point of view to expose patients for threatening information and atrocity propaganda only because some studies have shown that patients who conceive their disease as severe are more compliant than others. (ibid,p. 53, my translation).

The results of this study indicate that it need not be necessary for patients, in this case parents, to conceive the disease and the consequences as a threat, in order to carry out the treatment. Here the confidence in the outcome of the treatment seems to be of greater importance (the test concerning "percent change in visual acuity versus probability of reducing the threat" lends some support to this thought. The significance was close to less than 0.05). However, there is no significant relationship between knowledge and probability of reducing the threat. It is more likely that this condition seems to indicate that it is the personal contact with the ophtalmologists and orthoptists that has been of importance. Another possible explanation is that the treatment was not so comprehensive or difficult to carry through.

Education of patients concerning different diseases and treatments very often has its starting point in the opinions of the health care personnel i.e. what they think is essential for effective management of the disease.

It is however very common that patients do not understand what they have been told. Many patients do not even have elementary anatomic knowledge such as the position of various organs in the body (Ley, 1982, 1977,). Moreover, patients frequently have misconceptions which prevent an understanding and that can lead to rejection of advice (Stoeckle and Barsky,1980; Stimson, 1974;).

Wikblad (1991) holds the opinion that:

> Patients are more cognitively active than is assumed and they are likely to "fill in" with their own ideas when they don't understand. .(p. 44.)

The present study, which is mainly based on the phenomenographic research approach, has shown that knowledge is important to compliance.

The phenomenograpcic research tradition not only aims at identification of different conceptions of phenomena; its aim is also to use these conceptions in connection with education. This is something, which has been rare when it comes to patient education.

According to Fallsberg (1991):

> The outcomes of learning is determined by an awareness of what distinguishes the individuals who receive the message. An important task is to base patient information on the soundest knowledge possible including what people's commonest conceptions of disease and treatment look like" (p.4).

Through knowledge about the many ways that patients conceive of their disease, for instance through a dialogue with the patient, asking what he already knows, misconceptions can be detected and alternative conceptions can be discussed. Many patients have an everyday conception of that which is to be learned. This fact makes it more difficult when it comes to patient education. It is easier if the patient is "empty" and the task is only to fill him/her up with new knowledge. But, new ways of acting and new ways of thinking must build on and modify or replace earlier ways of acting and thinking. It is important to replace certain of the patient's conceptions of the disease and its treatment with conceptions, which are more adequate for an understanding of the disease, and to be able to carry out the treatment.

The present study shows that there is a relationship between understanding and compliance. On the other hand there is no relationship between the way of giving information and relationship between the way of giving information and compliance. Informing the patient about the disease and its treatment, by means of e.g. verbal communication, leaflets and booklets, has long been the principal method of obtaining compliance, but information does not automatically lead to understanding of the disease and treatment.

The pedagogy applied here is only one of possibly a number of alternative tools of intervention. It could be argued that understanding is of vital importance, regardless of how we approach the domain of patient communication and patient education, the understanding is of vital importance. Furthermore, we have good reasons to assume, that if health care personnel have knowledge about, and an understanding of, patients' different ways of thinking, they would be better prepared to intervene by instructing patients or, as in this case, the parents, in a more proper and adeuate way.

The way to the understanding that leads to a compliant patient, lies firstly within the field of knowledge about patients' conceptions and secondly how we transform this knowledge to information and patient education. According to Dahlgren (1990) knowledge can be entitled to one, or a combination of (a) *naming* phenomena and their properties, (b) *understanding* the nature of the phenomena and (c) *acting* in relation to the phenomena. As has been shown in this study, understanding leads to compliance, indicated by an increase of visual acuity, that is acting. How do we create understanding that leads to acting? This question is answered in one way, by Eggen and Kauchak, (1988). They think that factors that could enhance an understanding, for instance by using strategies that allow interaction with the learner/patient, are important.

I think that another aspect, when trying to approach the problem, is the use of educational methods which emphasise activity, starting from the patients' questions. I also think the problem is mainly within the educational field. When trying to approach the problem of how to get patients acquire an understanding that leads to acting, i.e. compliance, we must understand that the problem has many aspects and entrances. The level of education is certainly an important factor, when trying to educate patients.

Being aware of conceptions held by patients of different diseases which are common and phenomena related with these diseases, makes it possible for health care personnel to understand what patients understand and - which is perhaps even more important -

what they misunderstand. This kind of knowledge we hold to be an important component of the professional competence of health care personnel.

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Appendix 1

Interview guide:

1. From your point of view: how do you experience the treatment of your child?

2. How do you think your child experiences the treatment?

3. Compared with other families, do you think that you have more/less/about the same trouble with the treatment?

4. When did you first get information about that your child has a visual defect?

5. Have you got information from the ophtalmological clinic about your child's type of visual defect?

6. Have you got information about the treatment? Who gave the information?

7. How is the treatment going to be carried through?

8. Have you got information about squint (in general), the anatomy of the eye (how it is built), the function of the vision?

9. Do you think that the information is enough? Should it be more? Should it be less?

10 Do you understand what the ophtalmologist/ orthoptist is saying?

11. How do you experience the visits at the ophtalmological clinic?

12. Is there anything you want to change when it comes to the visits at the ophtalmological clinic?

13. Can you tell the staff at the ophtalmological clinic if you haven't attended to the treatment?

14. Do you think that the ophtalmologist and the orthoptist have an understanding for a) the child's situation when prescribing the

treatment? b) that problem might come up when carrying the treatment through?

15. Do other children tease the child? Reason: patch/spectacles/other things?

16. Are there any practical drawbacks to have reduced vision in one eye? a) In the short run? b) In the long run?

17. Which is the meaning of refractive error?

18. Which are the effects of strabismus on binocular vision and amblyopia?

19. Which are the conditions for the development of normal vision?

20. Which are the reasons for treatment with occlusion and with glasses?

21. Which are the reasons for an early onset of the treatment?

22. Which are the reasons for surgical treatment of strabismus?

23. Does monocular vision improve after surgery?

24. Is the patient able to avoid wearing glasses after surgery?

25. Which is the determinant of the duration of the treatment?

26. Which are the effects of an onset of treatment around the age three or at the age of fifteen?

27. Are there any negative short-term effects?

28. Which eye is covered in occlusion?

29. Which are the effects of strabismus on vision?

30. Which are the consequences of interrupting treatment?

31. Which are the consequences of interruptions of the treatment for a month?

Appendix 2

		Does not Agree			Agree	
		Absolutely	Partly	Don´t know	Partly	Absolutely
1	My child is more susceptible to infections than other children.	☐	☐	☐	☐	☐
2	The strabismus gives us more problems than other families have.	☐	☐	☐	☐	☐
3	The hospital personel often has a negative attitude.	☐	☐	☐	☐	☐
4	The strabismus influences the social life.	☐	☐	☐	☐	☐
5	When I have got medicin I have taken it exactly according to the prescriptions.	☐	☐	☐	☐	☐
6	At the hospital they do not understand how lonley and anxious you feel inside, even when they tell you that the child is rather well.	☐	☐	☐	☐	☐
7	I believe that the personel thinks that we manage the situation well.	☐	☐	☐	☐	☐
8	Sometimes my child is mobbed by his comrades because of the strabismus.	☐	☐	☐	☐	☐
9	I do not care so much about the child´s visual acuity, the main thing is that he feels well.	☐	☐	☐	☐	☐
10	The child must be let to go a little easier on the prescriptions when it is small and needs ”the time to play”.	☐	☐	☐	☐	☐
11	The doctors I have called on have always shown empathy for me and my diseases.	☐	☐	☐	☐	☐
12	I will not tell the doctor or the orthoptist that we do not always do as we are told.	☐	☐	☐	☐	☐
13	If you neglect the prescriptions a couple of times in a week it might in the long run have undesirable consequences.	☐	☐	☐	☐	☐

14 You can not live like other people with a strabismic child in the family. ☐ ☐ ☐ ☐ ☐

15 The child has not the same possibilities that other children have to get the employment it wants, because of the visual defect. ☐ ☐ ☐ ☐ ☐

16 The personel at the nursery school has sympathy for the childs´visual handicap and required treatment. ☐ ☐ ☐ ☐ ☐

17 I feel it hard to work to keep a check that the child gets enough vitamins and nutritive substances. ☐ ☐ ☐ ☐ ☐

18 In spite of the trouble with the controls/repeated visits, I feel them as a security. ☐ ☐ ☐ ☐ ☐

19 When a child goes to a party, it must not have eye patch/spectacles - if it not want. ☐ ☐ ☐ ☐ ☐

20 The father is most responsible for how the child behaves. ☐ ☐ ☐ ☐ ☐

21 Sometimes I have felt that the doctor thinks that I consult him for a mere trifle. ☐ ☐ ☐ ☐ ☐

22 I know what the consequences are if the treatment of the strabismus is not carried out. ☐ ☐ ☐ ☐ ☐

23 I know who to turn to if I or any other in the family fall ill. ☐ ☐ ☐ ☐ ☐

24 You catch diseases "if you shall have them" even if you take care of yourself strictly. ☐ ☐ ☐ ☐ ☐

25 We have noted that the child sees better when we have followed all prescriptions. ☐ ☐ ☐ ☐ ☐

26 One feels silly when one must go to several controls for the same disease. ☐ ☐ ☐ ☐ ☐

27 The days before control is due, it happens that I more carefully supervise that the child wears eye patch/spectacles. ☐ ☐ ☐ ☐ ☐

28 I hardly ever take my temperature	☐	☐	☐	☐	☐
29 Even if I am not directly ill I want to do a health control occasionally.	☐	☐	☐	☐	☐
30 Bad health is often due to the neglecting of onés health.	☐	☐	☐	☐	☐
31 The child welfare centres are too passive when it comes to remit suspected squinting to an eye specialist.	☐	☐	☐	☐	☐
32 I have to feel definitely ill before i go to a doctor.	☐	☐	☐	☐	☐
33 What I know about squinting I have picked up by reading, or got to know by friends and acquaintances.	☐	☐	☐	☐	☐
34 I believe that if the child carries eye patch or spectacles it is the best chance that it will see better	☐	☐	☐	☐	☐
35 An acute illness can also influence the eye sight.	☐	☐	☐	☐	☐
36 I prefer to keep silent than having my child feel that I nag, when I notice that it neglects to carry eye patch/spectacles.	☐	☐	☐	☐	☐
37 Notwithstanding that we have followed the prescriptions the child has not become better.	☐	☐	☐	☐	☐
38 The comrades treat my child as any other pal.	☐	☐	☐	☐	☐
39 The whole family helps to mind that the child follows the prescriptions.	☐	☐	☐	☐	☐
40 We often and gladly talk about family matters and problems at home.	☐	☐	☐	☐	☐
41 The child's squinting has affected me socially.	☐	☐	☐	☐	☐
42 The child's squinting takes more time from me, with the consequence that I have less time off.	☐	☐	☐	☐	☐

43 What the father says and does is as important as the efforts of the nursing staff ☐ ☐ ☐ ☐ ☐

44 Now it works excellent with the prescriptions we have to follow. ☐ ☐ ☐ ☐ ☐

45 The mother is the one most responsible for how the child conducts itself. ☐ ☐ ☐ ☐ ☐

46 The treatment of the squinting child has influenced the whole family. ☐ ☐ ☐ ☐ ☐

47 The squinting can disappear when the child gets older. ☐ ☐ ☐ ☐ ☐

48 I do not always believe that the doctor is right when he alters the prescriptions. ☐ ☐ ☐ ☐ ☐

49 It is important that I make the child understand that it must behave in the same way during the whole period of treatment. ☐ ☐ ☐ ☐ ☐

50 I make sure that I get to know all what I want before I leave the medical examination. ☐ ☐ ☐ ☐ ☐

51 What mother says is as important as the efforts of the nursing staff. ☐ ☐ ☐ ☐ ☐

52 To be sure you have to try yourself, and not rely entirely on the prescriptions you get at the ophtalmological clinic. ☐ ☐ ☐ ☐ ☐

53 I have got what I expected at my visits at the doctor. ☐ ☐ ☐ ☐ ☐

54 At the controls they only look at the test results, and do not care how the treatment influences the child's life besides. ☐ ☐ ☐ ☐ ☐

55 I am almost never ill. ☐ ☐ ☐ ☐ ☐

56 I really do feel that they want to help me, when I come to the hospital. ☐ ☐ ☐ ☐ ☐

57 In my present situation it is difficult to get time to take interest in friends and acquaintances. ☐ ☐ ☐ ☐ ☐

58 To carry eye patch/spectacles does not agree with child. ☐ ☐ ☐ ☐ ☐

59 It is difficult to understand prescriptions and advises. ☐ ☐ ☐ ☐ ☐

60 The staff at the ophtalmological clinic has studied the child so closely, that therefore we give more time to treatment. ☐ ☐ ☐ ☐ ☐

61 I believe that the child gets the best possible help at the ophtalmological clinic. ☐ ☐ ☐ ☐ ☐

62 What I know about squinting I have mostly learnt at the ophtalmological clinic. ☐ ☐ ☐ ☐ ☐

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